Bridging Social Science and Medicine to Improve Health

Department of Medical Social Sciences

The First Five Years and Looking Ahead
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A Message from the Chair

Dear Colleagues and Friends,

Five years ago, our Dean, Provost and President agreed to a historic move: to start a new department in the Northwestern University Feinberg School of Medicine (Feinberg) designed to be a home base for social scientists applying their many and varied methods to improve health. The Department of Medical Social Sciences, or “MSS” as we call it, was launched in March 2009. In only five years, we have grown from a vibrant outcomes research group of 14 scientists, to a unique interdisciplinary academic department of nearly 40 faculty. Our ranks have expanded to include physician-scientists, neuroscientists, health, developmental, quantitative and clinical psychologists, sociologists, statisticians and psychometricians.

Together, we conduct basic and applied social science research to advance the understanding of the mechanisms and measurement of health and disease. Our goal is to improve health and quality of life and to reduce disease burden. Our departmental growth has included recruitment of senior scientists whose leadership, scientific work and transformational perspectives have played a defining role in shaping our new field and new department. We are also extremely fortunate to have trained a cadre of junior scientists who have readily lent their energy, commitment and creativity to our department's evolution. When we started this journey, I could hardly have imagined the broad, deep and vital collection of scientists that MSS would become, and the valued place it has achieved within the Northwestern community. It is a rare privilege to take a vision from dream to reality, much less to have this reality soar beyond all of our expectations.

DAVID CELLA, PhD, Chair of the Department of Medical Social Sciences and Director of the Center for Patient-Centered Outcomes - Institute for Public Health and Medicine.
What makes MSS unique? Our broad scope, our collaborative orientation and our stellar leaders, who provide ideas and energy that transcend narrow, discipline-bound perspectives. We are fortunate that Northwestern’s longstanding culture of collaboration provides an outstanding platform to achieve our mission: working outside traditional disciplinary boundaries to improve health. In our first five years, we have actively collaborated with colleagues in the Institute for Public Health and Medicine (IPHAM), the Robert H. Lurie Comprehensive Cancer Center, as well as colleagues from other Feinberg departments, such as Preventive Medicine, Psychiatry, Medicine, Surgery, Neurology and Urology. Together, we have positioned Northwestern as a premier academic center for transdisciplinary biobehavioral research, as well as for outcomes and health services research by:

- Advancing outcome measurement and application via the development and dissemination of common metrics
- Enhancing physical, mental and social well-being of people with acute and chronic health conditions
- Developing novel methods for characterizing and reducing health inequities in vulnerable populations
- Promoting the discovery of multidimensional mechanisms of health and disease, from pregnancy to end of life

MSS continues to foster an environment enhanced by a significant number of intradepartmental, interdepartmental and center/institute collaborations. We have forged new directions with like-minded scientists in schools and programs that span the entire University. Some examples include:

- Institute for Policy Research and its Cells to Society (C2S): The Center on Social Disparities and Health
- Judd A. and Marjorie Weinberg College of Arts and Sciences: Sharing faculty across schools
- School of Communication (Communication Sciences and Disorders)
- School of Education and Social Policy
- Robert R. McCormick School of Engineering and Applied Science (Department of Industrial Engineering and Management Sciences)

Each and every faculty member at MSS is engaged in an academic culture that links departments and campuses and transcends units or disciplinary boundaries. We are creating exciting breakthrough studies that will not only improve overall health, but also quality of life for diverse individuals across the lifespan.

We are happy to be a part of the Northwestern family, and truly appreciate the encouragement and support we have received in growing our vision. Thank you for joining us in this celebration of our first five years and we look forward to our next five years with eager anticipation.

Sincerely,

David Cella, PhD
Professor & Chair
In order to improve health, we need to be able to evaluate its physical, mental and social aspects across the lifespan. Health measurement is essential to the provision of patient centered, responsive, evidence-based and cost-effective healthcare. To realize national mandates linked to the Affordable Care Act, we must improve how we measure health to ensure its relevance to patients and families. MSS faculty are renowned for leading the national trend toward measuring health from the perspective of people directly affected by a range of physical and mental disorders.

Cancer-Related Physical & Psychosocial Initiatives
Since our inception in 2009, MSS has served as the national epicenter for excellence in measurement science and application. Patient centered health measures are, by definition, important. Unfortunately, they are only infrequently used in healthcare because they are not easily linked to meaningful clinical action. Further, there is an over-abundance of measures of essentially the same things. Because many disparate measures make comparison across health conditions and studies difficult, our founding Chair, David Cella, developed a unique vision:

To create unified patient reported outcomes (PROs) to measure common symptoms, values and functions of life which enable the patient’s voice to be heard as an empirically validated part of decision-making for healthcare at an individual and societal level.

To enable this vision, MSS had led three major initiatives framed by the National Institute of Health (NIH) as promoting 21st century advances in clinical research and population health:

- The Patient-Reported Outcomes Measurement Information System (PROMIS®): An NIH Common Fund initiative to standardize measures of symptoms and function across a host of chronic diseases
- Quality of Life Outcomes in Neurological Disorders (Neuro-QoL): An NIH initiative to standardize measures of symptoms and function across neurological disorders
- The NIH Toolbox for Neurological and Behavioral Function (Toolbox): An NIH Neuroscience Blueprint initiative that creates standardized measures to efficiently assess cognitive, sensory, motor and emotional function across the lifespan

The over-arching goal of all these initiatives has been to create standardized measures to assess quality of life for the US population that apply across a wide range of clinical conditions. The measurement tools constructed and authenticated by MSS have led to a web-based “Assessment Center” platform, which serves as a new national resource for all to use. Recent applications of these approaches include:

- PROsetta Stone: A project that links highly similar measures of the same concept using a novel score linking approach to produce a common language for PROs
- National Children’s Study: In collaboration with the IPHAM Center on Healthcare Studies, we are managing field collection across ten states and leading the effort to develop measures of health for this largest-ever study of US children’s health

Making the Vision a Reality
Under the leadership of David Cella and Richard Gershon, along with the commitment, energy and contributions of many MSS faculty, these
initiatives have been tremendously successful. We are especially proud of MSS scientists who began their careers with us and have developed novel applications of patient centered outcomes research.

**Ahead of the Curve. Leading The Way.**
The deep bench of expertise of more than two dozen MSS interdisciplinary scientists and researchers place us at the forefront of modern healthcare research. From our foundational experience in patient centered outcomes, psychometrics and health information technology, we have now broadened our methodological bandwidth to include cutting-edge quantitative scientists in causal and longitudinal modeling and comparative effectiveness research, such as Dan Mroczek and Ryne Estabrook.

Going forward, we will continue to expand our collaborations within the university and across the nation to advance the use and application of measurement science to improve today’s healthcare.

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**LEADERS AND INNOVATORS**

**Richard Gershon, PhD** studies the intersection of measurement with technology to enable the development and application of assessment tools for numerous disciplines and across diverse domains over the lifespan including: cognitive functioning, achievement, emotional health, physical, motor and sensory function. He often turns to Item Response Theory and Computer Adaptive Testing to increase test efficiency and enable comparisons over time and across studies. He has leveraged this expertise to serve as an investigator and/or consultant on more than 100 assessment development projects in healthcare, education and medical certification.

**Jin Shai Lai, PhD, OTR** studies quality of life, symptom management and late effects due to chronic illness and its treatment for both pediatric and adult populations with a history of pediatric brain tumor. She is developing a PRO measurement system that extends across the lifespan to capture long-term quality of life and cognitive function sequelae in pediatric brain tumor survivors.

**Nan Rothrock, PhD** is an expert in utilizing Health Information Technology (HIT) to capture PROs as a means of improving clinical care. Her work advances PRO applications via her technical advisory role on the use of the Assessment Center platform for efficient integration of PROs into a range of clinical investigations.

**Zeeshan Butt, PhD** examines the development and application of PROs to measure surgical recovery in organ donors and recipients. Zee also catalyzes integration of patient centered outcomes into clinical care through leadership roles in the NU Transplant Outcomes Research Collaborative (NU-TORC) and the IPHAM Center for Patient-Centered Outcomes.
The burden of disease affects every aspect of our society. Despite major advances in prevention, early detection and treatment, it is vital to develop novel, evidence-based strategies to prevent and manage major health conditions.

At MSS, researchers are making major contributions to the science of health promotion and disease management. These build creatively on the complex and multidimensional nature of the determinants of health and disease and employ the multilevel strategies necessary to reduce morbidity and mortality for diverse individuals across the full disease spectrum and the lifecourse. Some of the themes that our group is addressing involve:

- Optimizing quality of life and health outcomes in cancer survivorship
- Promoting health and preventing HIV/AIDS in the LGBT community
- Optimizing care transitions as an opportunity for health promotion

Many of these endeavors capitalize on our cutting-edge work in applications of Health Information Technology (HIT).

**Cancer-Related Healthcare Delivery and Quality of Life Initiatives**

The Cancer Control and Survivorship Program and the Cancer Survivorship Institute at the Robert H. Lurie Comprehensive Cancer Center are directed by Frank Penedo, with contributions by many MSS faculty. Together, they develop and test innovative techniques for palliation of cancer-related symptoms and reduced quality of life via psychosocial interventions such as:

- Evaluating the efficacy of technology based/web-delivered stress management and symptom palliation in advanced prostate cancer
- Exploring the reduction of anxiety and fear of recurrence in breast cancer survivors
- Using HIT in real time to address symptom monitoring in adult and pediatric oncology via the Symptom Monitoring (SyMon) Practice Improvement Program
- Examining the role of integrative medicine, such as mindfulness interventions, to manage stress and aid treatment decisions
- Developing and evaluating the implementation of electronic health records (EHR) integrated and automated cancer survivor treatment summaries and care plans

**Care Transition Efforts to Maximize Health Outcomes**

MSS physician-scientists, like Craig Garfield and Mitesh Rao, are exploring care transitions in at-risk populations as a window of opportunity for maximizing care and health outcomes during the key transition from acute/tertiary care to home-based care. These include:

- Developing a novel smart phone intervention for parents to optimize health outcomes for their infants during the transition from the Neonatal Intensive Care Unit (NICU) to home
- Testing how the ER can become a nexus for care coordination to reduce unnecessary hospitalizations and enhance treatment adherence for HIV/AIDS patients
The Impact of Health Promotion for the Lesbian, Gay, Bisexual and Transgender (LGBT) Community

Prevention of HIV and health promotion in HIV seropositive individuals continue to be critical public health issues for the LGBT community—especially for adolescents and young adults. The MSS IMPACT Program, directed by Brian Mustanski, addresses these issues with creative study designs ranging from epidemiologic observations and methods development, to online interventions and public health initiatives for young men who have sex with men (YMSM).

The ongoing work by our IMPACT Program scientists include some of the first epidemiologic studies to document the pattern of health issues and their amplifiers, such as discrimination and victimization that:

- Contribute to YMSMs’ health risks over the life course
- Test the utility of innovative online programs for health promotion and to reduce HIV risk
- Delineate how YMSMs’ social networks accelerate or buffer HIV transmission
- Elucidate the role of families in physical and mental health of YMSM
- Test effectiveness of self-test kits as a public health strategy for increasing HIV testing

In the future, MSS will continue to develop patient centered strategies and feasible, evidence-based tactics to prevent chronic diseases and manage major health conditions. Our long-term goals are particularly focused on helping to find health management answers for those in our community who are most vulnerable and most at risk.

LEADERS AND INNOVATORS

Frank Penedo, PhD studies how psychosocial and cultural factors impact health related quality of life and chronic disease outcomes in cancer, cardiovascular disease and HIV/AIDS in diverse populations. His work involves evaluating the effectiveness of technology-based psychosocial interventions in improving health and understanding how biobehavioral mechanisms can influence disease activity, with emphasis on neuroendocrine, immune and inflammation pathways.

Susan Yount, PhD investigates how HIT can be used to enhance symptom management and quality of life in patients with chronic illness, such as pulmonary disease, cancer and organ transplantation. Her studies have utilized electronic symptom management assessments that provide physicians with real time feedback to improve care.

Mitesh Rao, MD designs and develops mobile navigation tools to increase patient and family engagement in decision making during emergency care. He also develops emergency room-based, community-engaged care linkage for chronic disease management to reconnect patients to both clinical care and community support.

David Victorson, PhD explores new ways to improve health and well-being in people diagnosed with cancer and other chronic diseases through dynamic measurement science, community engagement, and delivery of face-to-face and technology enabled mind-body, psychosocial and bio-behavioral interventions. He is particularly interested in the use of mindfulness interventions to reduce overtreatment in cancer survivors.
Increasingly, there is recognition of the potent impact of development on disease onset and course, and the intersecting influences of brain, physiology and behavior on these patterns. Building on our robust collection of health measurement tools, MSS experts in developmental science, causal modeling, neuroscience and psychoneuroimmunology have broken new ground in the investigation of these complex and mutually interacting influences on disease patterns. Uncovering mechanisms that impinge upon disease course and expression at varying stages of the life course is crucial to maximizing the impact of prevention and treatment, thereby reducing the burden of disease.

**Developmental Mechanisms of Disease**
MSS scientists explore developmental factors that help explain individual differences in health and disease trajectories ranging from pre-birth influences to factors that predict mortality:

**Early Life Origins of Disease Susceptibility**
Recent scientific advances provide us with unprecedented capacity to pinpoint diseases at their origins. While research has traditionally looked at how adverse early experiences are linked to adult disease, there is a major gap in understanding how and for whom these adverse experiences impact disease susceptibility. MSS scientists are exploring new methods to identify these early developmental susceptibility markers before disease onset.

The MSS Developmental Mechanisms Program, under the direction of Lauren Wakschlag, has set standards for the field by infusing a developmental perspective into this scientific arena. This group is one of the first to translate The National Institute of Mental Health’s (NIMH) mandate for dimensional reconceptualization of mental disorders into measurable terms, generating scientifically-based thresholds that provide robust indicators of susceptibility to mental health problems very early in life. Developmental, neuroscientific, community health and pediatric experts at MSS are advancing the science of early life disease pathways and prevention in both basic and applied ways:

**Basic Discovery**
- Shaping a developmental understanding of how prenatal exposure to cigarette smoke links to later mental health risks
- Employing state-of-the-science modeling methods to explore how the prenatal environment interacts with genetic risk in susceptibility pathways
- Utilizing neuroimaging tools to decode the neural basis of disease onset and quality of life
- Conducting a decade long study to pinpoint the specific disruptions in early childhood brain and behavioral development that mark the onset of chronic mental disorder

**Application**
- Testing whether promoting parental mental health and engagement during the perinatal period can improve outcomes, even prior to birth

**The Contribution of Personality to Life-Course Health**
At the other end of the lifespan, MSS quantitative scientists in the Lifespan Personality and Health Program, led by Dan Mroczek, are...
investigating how variations in personality and other psychological factors influence disease susceptibility and long-term health. An individual's personality patterns over time may influence health outcomes and trajectories in adulthood, including cardiovascular events, the onset of dementia and other mortality risks. Indeed, this concept of individual difference is the basis of personalized medicine. To achieve this, MSS scientists are employing a pioneering strategy known as Integrated Data Analysis to leverage more than 40 longitudinal datasets representing 70,000 individuals worldwide.

The Contribution of Biology, Culture and Behavior to Health Outcomes
To better understand disease course and to favorably impact health outcomes, it is critical that we consider multiple determinants of these chronic conditions. Our Biopsychosocial Mechanisms and Health Outcomes program, led by Frank Penedo, seeks to discover why diverse individuals with the same disease show different outcomes. The program emphasizes variations in psychosocial stress, processes and culture. In particular, we examine how psychosocial stress impacts endocrine and immune regulation, inflammation and gene expression. This enables us to test how variations in stress responses and other factors impact health related quality of life, symptom burden and health outcomes via differential psychosocial and physiological responses. This includes:

- Testing whether stress management and mindfulness interventions reduce symptom burden by regulating immune and endocrine function in cancer populations
- Examining whether stress-reduction's impact on symptom burden and quality of life varies for individuals based on cultural context and psychosocial experience and traits
- Exploring whether psychosocial stress and inflammation contribute to health outcomes, including cancer related cognitive dysfunction and stem cell transplantation
- Evaluating the extent to which sociocultural factors influence intermediate behavioral and physiological risk factors of cardiovascular disease in Hispanic/Latino populations

In the future, we will continue to pursue our investigation of markers and underlying mechanisms that shape the onset and course of disease. These can then be translated into high impact prevention programs tailored to reduce disease burden and promote lifespan health.

LEADERS AND INNOVATORS

Lauren Wakschlag, PhD is a developmental, translational scientist who studies phenomenology, mechanisms and prenatal origins of early emerging disruptive behavior. She is an expert in developmentally-sensitive measurement and has created a unique set of dimensionally-based assessment tools to distinguish the normative misbehavior of early childhood from clinically salient patterns. In multiple longitudinal studies of disruptive behavior mechanisms, she has modeled the impact of prenatal exposure to cigarettes, modifying effects of genetic susceptibility and parenting environment, and characterized its neurodevelopmental substrates.

Ryne Estabrook, PhD develops and applies statistical methods for measuring individual, family or group health outcomes over time. These methods can separate between-person differences (e.g., traits) from within-person change over time (e.g., states) to better assess variation in health and to distinguish associations from causal relationships.

Joel Voss, PhD studies the brain mechanisms for mental health and quality of life, including their developmental origins and impairments in neurological and neuropsychiatric disorder. He is an expert in the development of novel tools for the sophisticated assessment of brain function and dysfunction that can be applied across the lifespan, including specialized neuroimaging, eye-tracking, and behavioral instruments.

Craig Garfield, MD, MAPP examines the role of parents, particularly fathers, in the health of children and families. He has developed an innovative smart phone technology to enhance parental engagement and self-confidence during the transition of their infants from the Neonatal Intensive Care Unit (NICU) to home.
The inequities in health outcomes due to poverty, sociocultural processes, access to care and discrimination are interconnected, cumulative, intergenerational and, sadly, increasing. A traditional medical approach begins with the disease or presenting problem. In contrast, a health equity scientific orientation first defines the community in question and then strives to address its unique health and healthcare needs with consideration of the social and cultural factors that influence them. Researchers at MSS are conducting complex studies to bridge these social science and medical approaches in order to find creative solutions for individuals and communities who bear the unequal burden of disease.

We have forged innovative community partnerships that have made major contributions to promoting health equity across a broad range of health outcomes such as:

- HIV/AIDS
- Cancer
- Mental health and drug abuse
- Reproductive health

Our approach to the science of health equity, along with developing measurement and intervention tools to reduce the unequal burden of disease, is closely aligned with community based participatory research methods. Many of our MSS faculty have partnerships with Chicagoland community-based hospitals, clinics and organizations that provide us with the opportunity to implement our research in “real world” settings to communities in need.

Evaluating Cancer Care Disparities Across the Continuum
Cancer survivors continue to experience critical disparities, despite efforts to address health equity and the unequal burden of the disease. MSS researchers are leading community-based ethnographic, observational and interventional studies focusing on topics such as:

- Obstacles to care for low income minority women needing diagnostic resolution and treatment for abnormal cancer screenings
- Patient navigation across the cancer care continuum to promote screening treatment compliance and follow-up care
- Health literacy and health disparities in ethnically diverse communities

MSS partners with the research component of an NIH Community Network Program that focuses on patient navigation among Hispanic cancer survivors. Our work also evaluates the influences of socioeconomic status (SES) and sociocultural measures such as acculturation, perceived discrimination, family interdependence and religiosity/spirituality. Factors such as these can help us better understand disparate quality of life outcomes among ethnic minority cancer survivors.
Reducing Health Disparities with Health Information Technology (HIT)

Some of our most innovative work applies our HIT to real-world settings that serve vulnerable populations. The “Talking Touchscreen,” developed by Beth Hahn, assesses health literacy in real time inside physicians' offices. This exciting work has the potential to reduce health disparities in low-literacy populations by specifically tailoring physician communication to a level that patients can understand. It has been adopted by the CancerHelp Institute’s patient education programs and Kaiser Permanente. Patient/physician communication is also targeted in the work of Karen Kaiser, which examines care disparities in women diagnosed with breast cancer and their influences on their clinical decision-making.

Addressing the Health Needs of the LGBT Community

The IMPACT LGBT Health and Development Program, directed by Brian Mustanski, is widely recognized as a national model in applying the best scientific methods to addressing health disparities of the LGBT community. IMPACT work spans the translational spectrum:

- Exploring epidemiologic studies of the prevalence of health issues with the LGBT community
- Pioneering longitudinal studies of the development of health issues and their causes
- Developing innovative prevention programs that build on scientific evidence to improve health
- Partnering with community and government organizations to implement effective health services

IMPACT has created a unique academic-community partnership with the Center on Halsted—the most comprehensive LGBT resource center in the Midwest. This onsite location allows MSS researchers to efficiently conduct studies, explore scientific applications and collaborate with the Center’s staff to improve the health of the LGBT community.

Our goal for the future is to continue to pioneer new methods to understand and eliminate persistent inequities in health, and to partner with the individuals and communities with the largest burden of disease who most need our help.

LEADERS AND INNOVATORS

**Brian Mustanski**, PhD conducts translational research on LGBT health ranging from epidemiological studies of the prevalence of health issues to longitudinal cohort studies examining the development of health problems and their causes to the creation of interventions and partnering with community organizations to deliver services. He is a leader in using new technology, like online soap operas and text messages, to help prevent HIV among young gay and bisexual men.

**Darius Tandon**, PhD is an expert in community-based participatory research, who investigates the development and implementation of interventions to prevent the onset and worsening of depressive symptoms in vulnerable populations. This includes creative approaches to embedding mental health services in community settings such as employment training programs for low-income young people and home visitation for pregnant women.

**Michael Newcomb**, PhD studies health disparities in substance use and mental health problems in LGBT youth and adults, and the role of HIT in reducing them. For example, he is examining the impact of online diaries as an intervention for reduction of sexual risk behavior in LGBT youth.

**Elizabeth Hahn**, MA focuses on enhancing patient centered care and improving health outcomes for underserved populations, especially those with limited literacy skills. Her “Talking Touchscreen” instrument integrates state-of-the-art measurement science and HIT approaches to assess health literacy in real time in physician waiting rooms for individuals with a range of chronic diseases.
The Transformative Power of Collaboration

At MSS, we believe patient centered and interdisciplinary approaches to research and health care are the foundation of truly personalized medicine. Research that occurs at the boundaries of disciplines is most likely to lead to innovative solutions to the pressing health problems society faces. Transdisciplinary collaboration—from discovery to application, from health measurement and promotion to disease management, and from basic mechanisms to population health—defines our past five years and frames our “big tent” scientific initiatives for the future.

Collaborative Partnerships at Feinberg to Foster Patient Centered Approaches
MSS outcomes expertise, our leadership of the IPHAM Center for Patient Centered Outcomes and our research technology platforms such as “Assessment Center” have led to engaging collaborations with clinical investigators throughout Feinberg. Our outcomes experts in measurement, outcomes evaluation, Health Information Technology (HIT), intervention science, and clinical trials design are partnering with Feinberg clinician-investigators in clinical departments and divisions such as Surgery, Urology, Neurology, Orthopedics, Pediatrics, Preventive Medicine, Psychiatry and Behavioral Sciences, General Internal Medicine, Infectious Diseases, Rheumatology and Emergency Medicine. Examples of our patient centered collaborations include:

Northwestern Medicine—Patient Reported Outcomes (NM-PRO) Initiative
The Northwestern Medicine—Patient Reported Outcomes (NM-PRO) Initiative is a partnership of MSS faculty with investigators from the IPHAM Center for Patient Centered Outcomes, the Departments of Orthopedics and Surgery and Northwestern Medicine Information Technology. NM-PRO is developing a cutting-edge integration of patient reported outcomes information with clinical practice and performance measurement. This NM-PRO integration of PROMIS® and related patient centered outcomes information is a proof of concept initiative in orthopedics that can be “scaled” into the evaluation of health care quality in other clinical areas.

A National Person Centered Assessment Resource (PCAR)
Based upon our previous work and current position on the national scene, we have conceived a national Person Centered Assessment Resource (PCAR). Our vision for PCAR is to be the “go to” place for a wide range of high quality, NIH-sponsored person centered and patient centered assessments. Led by David Cella, with core directors Karon Cook, Richard Gershon, Nan Rothrock and Susan Yount, PCAR is designed to sustain a research resource infrastructure that will educate researchers and health professionals on the use and interpretation of person centered health outcomes. Scaled for widespread use, its overarching goal is a sustaining interest in our large trans-NIH measurement studies—PROMIS®, Neuro-QoL and NIH Toolbox. PCAR draws on MSS capabilities in:

- Psychometrics
- Survey research methods
- Biostatistics
- Population science
- Software design
- Electronic data capture
- Technical support
- HIT integration
- Educational methods
- Website design
- Marketing and communications
- Business development
Translational and Cross-Campus Collaborations

MSS faculty's broad expertise in disease causes, courses and mechanisms has led to rich collaborations with methodological, theoretical and population health scientists across NU’s medical and social science campuses.

Transdisciplinary Cancer Research

Robert H. Lurie Comprehensive Cancer Center’s Cancer Survivorship Institute, directed by MSS faculty Frank Penedo, promotes research in cancer survivorship and addresses factors such as:

- Environmental
- Sociocultural
- Behavioral
- Psychosocial
- Neuroendocrine
- Immunological
- Neurobiological
- Genetic

The Institute’s alignment with the supportive oncology and cancer survivorship specialty clinics care initiatives, and its focus on biobehavioral oncology research, provides ideal transdisciplinary research platforms to enhance the survivorship experience. For example, survivorship experts are collaborating with MSS neuroscientist Joel Voss to pinpoint chemotherapy-induced neural alterations that impact quality of life and neurocognitive function in breast cancer survivors.

One burgeoning area of collaborative activity is between MSS researchers and physician-scientists in Hematology-Oncology (Hem-Onc). Frank Penedo, Psychology/IPR faculty and MSS affiliate, Gregory Miller, and Hem-Onc’s John Galvin are developing an innovative approach to studying psychosocial determinants of symptom burden, quality of life and survival in stem cell transplant recipients. Beth Hahn and David Cella are collaborating with Hem-Onc’s Frank Giles to develop an integrated drug development program combining patient reported outcomes with genetic and clinical information in Phase I/II treatment trials. This will identify early signs of significant toxicity and signals of individualized benefit. Sofia Garcia and Hem-Onc’s Sheetal Kircher are evaluating how psychosocial factors impact disease activity via inflammatory pathways in colorectal cancer survivors to improve survivor well-being.

David Victorson, and IPR scientists Thomas McDade (Anthropology) and Emma Adam (School of Education and Social Policy) are investigating effects of mindfulness meditation on stress biomarkers in young adults with cancer.

Leading the Way in “Big Tent” Science

MSS faculty are also leaders in “big tent” science, as exemplified by two diverse initiatives in the NIH pipeline. Brian Mustanski, Infectious Diseases’ Richard D’Aquila and a host of collaborators from MSS IMPACT, Infectious Diseases, Pathology, and Industrial Engineering and Management Sciences are proposing an innovative “U01” study to conduct one of the largest and most comprehensive studies that examine the social dynamics of HIV transmission in young men who have sex with men.

Led by Lauren Wakschlag, the “NUBridge” program project (P01) proposal is a collaboration of more than two dozen leading Northwestern scientists, spanning Feinberg, the Institute for Policy Research, four schools and eight departments. NUBridge’s innovation lies in its integrated examination of neurobiology and social inequality as mechanisms by which pre- and post-natal stress impact gestational biology, neural systems and regulation of behavior in the first two years of life.
During the first five years of MSS, we have been blending social science and biomedical approaches across traditional disciplinary boundaries to generate novel solutions to the pressing health issues of our time. Our researchers and scientists have been developing a new energetic culture of engagement and opportunity.

However, because MSS is the first program of its kind in the nation, there is no existing roadmap for training our future scientists. Most training programs are focused on traditional medical disciplines, with few skills learned to bridge the gap between basic and applied science. At MSS, we emphasize transdisciplinary collaborative science as a means of building this important bridge.

Developing Emerging Training Models

One major thrust for innovating MSS models has been training physician scientists to integrate social science methodology into their research. We’ve approached training from many angles and at many stages of career development. While some of our initiatives are already in place, others are still being developed. But the unifying elements of our educational programs encourage disparate areas of medical and social science to grow and blend together in order to transmit a harmonized, integrative approach, with a strong emphasis on person centeredness, diversity and health equity. Here are some examples of our developing training programs:

- Northwestern University Patient-centered Intervention and Engagement Training (NU-PATIENT) – Under the direction of Dr. David Cella, and in collaboration with IPHAM, NUCATS and IPR leadership, we have generated cutting-edge models and programs to train the next generation of patient centered scholars. The goal of all these initiatives is to conduct high impact research that blends comparative effectiveness and patient centered engagement methods. The NU-PATIENT K12 training program weaves together pockets of excellence across medical and social science campuses to create an integrated patient centered training network. It will include faculty from nine Medical School departments—from Preventive Medicine to Emergency Medicine—and seven departments from other schools across the university, from Statistics to Engineering and Management. The NU-PATIENT K12 institutional career development program has been enthusiastically received by AHRQ and, if funded, will provide support for 10 diverse junior faculty scholars. The program’s emphasis will be on deep and broad transdisciplinary training and support geared towards scientific launching.

- IPHAM Health Sciences Integrated PhD Program – MSS is an active partner in the IPHAM Health Sciences Integrated PhD Program, directing the translational outcomes science track led by Cindy Nowinski. By providing a welcome home to medical students, graduate students and postdoctoral fellows, we help them gain the methodological and substantive skills they seek that can be applied to a range of diseases.

- Northwestern University Interdisciplinary Innovations in Developmental Education And Sciences (NUIIDEAS) – Led by Lauren Wakschlag, and in collaboration with leading scientists from both campuses, NUIIDEAS is an initiative designed to create an interconnected network of social and biomedical scientists focused on early development and its implications for lifespan health. NUIIDEAS is partnering with The Graduate School to create a cross-campus graduate cluster, bringing together more than 100 Northwestern University scientists spanning fields as diverse as:
  - Anthropology
  - Psychology
  - Human Development
  - Communications Sciences
  - Preventive Medicine
  - Psychiatry
  - Pediatrics
  - Maternal-Fetal Medicine
Its goal is to cross-train scholars to conduct high impact science that translates discovery from basic developmental science to scientific applications designed to alter the developmental origins of disease susceptibility.

- **Research Opportunities, Academic Development & Mentorship to Advance Professional Skills (ROAD MAPS)** – ROAD MAPS, led by David Victorson, has enhanced our training presence on the Evanston campus by providing hands-on clinical research training to dozens of pre-med and other undergraduates, graduate students and postdoctoral fellows in:
  - Mind-body Medicine
  - eHealth
  - Health Disparities
  - Measurement Science
  - Community Engaged Research

- **Feinberg School of Medicine Medical Student Teaching and Mentorship** – The Feinberg School of Medicine College Mentor is a four-year appointment that is one of the most important teaching responsibilities within the medical school. As a College Mentor for the Class of 2011, Craig Garfield, MD, MAPP was assigned one quarter of the incoming medical school class. He served as the go-to-guide for their personal and career development over the four years of medical school.

MSS Faculty Cindy Nowinski, Nan Rothrock and Susan Yount also play an active role in medical student curriculum development and teaching. This includes serving as Scholarly Concentration advisors, as well as shaping and implementing the Health and Society curricula for oncology, pulmonary medicine, and lifestyle and medicine modules.

**Promoting Diversity**

MSS is also deeply committed to the development of training opportunities to foster diversity in the medical social sciences scholarly workforce and prepare scientists to work with diverse and under-served communities. We house an NIH planning grant to address cancer disparities in cancer control and survivorship. This collaboration with Northeastern University, an institution that serves the Hispanic community, supports several junior scholars via NIH supplements.

Brian Mustanski’s IMPACT program partners with the Center on Halsted, the Departments of Psychiatry and Behavioral Sciences, and Infectious Diseases to conduct the first HRSA-funded, pre-doctoral psychology internship program in the country focused on providing culturally competent mental health services to the LGBT community.

As we continue to grow as a unique new department, our innovative training methods and interdisciplinary educational programs will grow with us as well. There can be no greater goal for the future of MSS than to train and educate the next generation of medical social scientists.

**EMERGING SCHOLAR HIGHLIGHTS**

**Sofia Garcia, PhD** examines methods of addressing the symptoms and concerns of individuals with cancer and other chronic illness to improve their health and quality of life, with an emphasis on underserved populations. She is currently developing and evaluating interventions, including the use of Health Information Technology (HIT), to assist cancer patients’ transition from active treatment to extended survivorship.

**Benjamin Schalet, PhD** pursues research to answer the question “What is the most accurate, efficient, and useful way to measure health and disease states?” He explores this within initiatives like PROsetta Stone to enable comparisons of PRO outcomes across varying health measures and by investigating how varying personality attributes are harmful or beneficial to health.

**Betina Yanez, PhD** examines the biologic, psychosocial and cultural mechanisms that underlie racial/ethnic disparities in patient reported outcomes among cancer survivors, particularly Latina women. She is currently studying the impact of web-based interventions for underserved populations, and adherence to cancer surveillance and hormonal therapies among Latina breast cancer survivors.

**Karen Kaiser, PhD** applies a social-ecological framework to examine individual, interpersonal, organizational, social, and policy influences on patient understandings of disease and health behaviors, outcomes and disparities. Her current work focuses on the contribution of quality of patient-physician communication, and cultural and media health messaging on surgical decision-making for breast cancer patients.
Over the past five years, MSS has grown into a unique interdisciplinary academic department that has been highly successful in developing new faculty connections and collaborations. Our scientific achievements have gained national and international recognition. We have expanded from a faculty of 14 to nearly 40, and from administration and research staff of fewer than 30 to more than 120. We now occupy 30,000 square feet of research space, excluding our satellite and community-based sites. Not only has our dream become a reality, but this reality has also soared beyond our expectations. We will enthusiastically continue to grow our vision and eagerly anticipate the next five years.

Successful Grant Proposals
Writing grant proposals is challenging and exacting. For example, since September 2010, Feinberg’s average proposal success rate is 36%, considered excellent compared to the national averages. Contributing to this overall Feinberg rate, the MSS proposal success rate over the past five years has been 38%-a tribute to the quality of our faculty grantsmanship. Our scope is broad. MSS scientists are funded by more than 10 federal institutions and agencies including:

- National Cancer Institute (NCI)
- National Institute on Aging (NIA)
- National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)
- National Heart, Lung and Blood Institute (NHLBI)
- National Institute of Nursing Research (NINR)
- National Institute of Neurological Disorders and Stroke (NINDS)
- National Institute of Mental Health (NIMH)
- National Institute on Drug Abuse (NIDA)
- Center for Disease Control (CDC)
- Agency for Healthcare Research & Quality (AHRQ)
- U.S. Department of Defense (DoD)

Most recently, we have added the new Patient Centered Outcomes Research Institute (PCORI) to the growing list of extramural funding agencies. We have reached this goal by recruiting high caliber scientists, placing a strong emphasis on mentoring our junior investigators and strategically targeting opportunities that best fit our scientific mission and goals. A leadership goal in 2013 was to engage in several “big tent” science opportunities and we have done so with multiple cross-cutting initiatives. We’re excited that FY14’s mid-year grant proposal amounts already exceed FY13’s total dollar amounts—and will help feed the MSS pipeline of future research funds.
Honors and Awards
Our faculty members have received many scholarly nominations, honors and professional awards at local, national and international levels. Some of these accomplished designations include Best Poster Award at the ISOQOL 20th Annual Meeting, New Investigator Award at the American Psychosocial Oncology Society and Keynote Speaker at University of Southern California’s 21st Annual Occupational Science Symposium.

In the last five years, we’ve received more than 350 invitations to speak, present, perform or exhibit at local and national conferences. A few examples include the National Committee for Quality Assurance (NCQA), Orthopaedic Trauma Association Annual Meeting, APA Symposium and American Transplant Congress, International Society for Quality of Life Research (ISOQOL) Best Paper Awards and David Cella’s election to the Academy of Behavioral Medicine Research.

Growing Our Staff of Specialists
MSS has grown from only three non-faculty founding employees in March 2009 to 120 staff members and post doctoral specialists in informatics, qualitative methods, psychometrics, statistical analysis, research operations and administration. While we hire and mentor aspiring staff with career goals of their own, some stay and acquire a graduate degree while working with us. We take pride in these achievements by current and former employees:

- 11 former research staff members are attending or have completed medical school
- 17 former and/or current research staff members are attending or have completed a master’s program
- 14 former research staff members are attending or have completed a PhD program

Working in Collaborative Research Space
The MSS workspace occupies 30,000 square feet of efficient and productive space including: dry lab research space, observational labs, subject interview rooms, pediatric behavioral observation rooms, neuroscience lab space, phlebotomy labs, a community outreach office with the Center on Halsted and joint shared space on the Northwestern University Evanston campus.
In 2013, the number of publications in peer reviewed journals has increased to twice as many as in our 2009 founding year, reflecting our scholarly productivity.

As MSS faculty has grown, Feinberg has helped us identify, plan and develop a productive and efficient workspace. Research space growth is directly linked to growth in research awards.
The size of our full research portfolio is evident by the increasing number of active grants and contracts per year. MSS is replacing grants and awards faster than the close of projects, which is a healthy indicator of success.

Each year, we have increased our total dollar amount due to the prolific work and tireless efforts of our MSS scientists. The successful recruitment of senior scientists with thriving research portfolios, as well as the diversification and expansion of our scientific activities are key contributors to our success.
Productivity (continued)

The funding portfolio in MSS is as diverse as our scientific interests. This chart represents various funding sources from the NIH, PCORI, private companies, non-profit foundations and state health funding agencies.

EXPENSE CATEGORIES
At MSS, we minimize overhead and maximize the investment in our faculty. We invest the majority of our resources in research faculty programs to drive scholarly activity, award funding and overall productivity.
*PER FACULTY

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*ANNUAL INCREASE OF 6 NEW FACULTY PER YEAR

SPONSORED RESEARCH DOLLARS PER FACULTY

Research metrics are an important measurement of efficiency and financial productivity. As MSS faculty grows, our overall output climbs.

ANNUAL

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SPONSORED RESEARCH DIRECT EXPENDITURES ANNUAL INCREASE

In five years, MSS has grown exponentially. Research expenditures increase each year, while we add new faculty, staff, collaborators, projects and initiatives.
Michael Bass, MS, Research Assistant Professor, provides programming and strategic input in technical matters related to information systems integration and patient-reported outcomes research. He plays an important role in creating cutting-edge health information technology infrastructure for implementation and dissemination of MSS’s many measurement science and intervention initiatives.

Michelle Birkett, PhD, Research Assistant Professor, seeks to identify the social and contextual drivers of health and well-being in vulnerable populations, particularly LGBT youth. Innovative applications of network and multilevel methodologies are used to coax apart the complex individual, social, contextual, and developmental factors influencing health equity.

Zeeshan Butt, PhD, Associate Professor (see Health Measurement and Application profile).

David Cella, PhD, Professor and Chair, is a pioneer in the field of patient centered outcomes science. He is widely recognized for his influential vision that health and healthcare are optimized and even transformed when the patient's voice is properly represented and understood. His work on patient reported outcomes has changed the face and best practice standards of clinical research. Dr. Cella’s research has had particularly high impact because of his commitment to rapid translation to application, including integration into clinical care, decision making and clinical trials.

Karon Cook, PhD, Research Associate Professor, uses her psychometric expertise to advance application and interpretability of patient-reported outcomes (PROs). Interpretability includes linking scores from different measures of the same outcome, generating cut scores to define clinical significance, anchoring PRO scores to functional patient states and providing patients with PRO results to promote self-management.

Ryne Estabrook, PhD, Assistant Professor (see Mechanisms of Health and Disease profile).

Sofia Garcia, PhD, Assistant Professor, (see Training the Next Generation profile).

Craig Garfield, MD, MAPP, Associate Professor of Pediatrics and MSS (see Mechanisms of Health and Disease profile).

Richard Gershon, PhD, Associate Professor & Vice Chair for Research, (see Health Measurement and Application profile).

George Greene, PhD, Research Assistant Professor, utilizes community-engaged research approaches to reduce health disparities in the HIV epidemic, particularly among young men who have sex with men in communities of color.

Jamie Griffith, PhD, Research Assistant Professor, uses psychometric methods to investigate connections among health-related concepts, including anxiety, depression, memory and pain. He is currently examining methods to promote symptom management and treatment planning in urology patients.

Elizabeth Hahn, MS, Associate Professor (see Promoting Health Equity profile).

Vered Hankin, PhD, Research Assistant Professor, focuses on incorporating integrative medicine techniques, such as meditation and yoga, to promote wellness in patients with chronic illness.
Sally Jensen, PhD, Research Assistant Professor, examines quality of life and patient-reported outcomes in a variety of medical areas including cancer, surgery, transplantation, HIV, chronic pain, and upper limb amputation. She is currently studying the assessment of patient-reported surgical outcomes in a variety of clinical conditions.

Karen Kaiser, PhD, Research Assistant Professor (see Training the Next Generation profile).

Michael Kallen, PhD, MPH, Research Associate Professor, applies psychometric methods to advance modern patient-centric approaches, which occur in electronic computing environments. These approaches are designed to take less time to complete while retaining hallmark validity and reliability characteristics. The development and appropriate use of screening items, computer adaptive testing and person response validity are ongoing areas of his work.

Maria Kharitinova, PhD, Research Assistant Professor, investigates cognitive and neural mechanisms of typical and atypical development in children.

Jin Shei Lai, PhD, OTR, Professor (see Health Measurement and Application profile).

Judith T. Moskowitz, PhD, MPH, Professor, studies the impact of positive emotion on adjustment to health-related stress. She is currently conducting multiple randomized trials to increase positive emotion and well-being in individuals coping with type 2 diabetes, stage IV breast cancer, HIV and caregivers of patients with dementia.

Michael Kallen, PhD, MPH, Research Associate Professor, applies psychometric methods to advance modern patient-centric approaches, which occur in electronic computing environments. These approaches are designed to take less time to complete while retaining hallmark validity and reliability characteristics. The development and appropriate use of screening items, computer adaptive testing and person response validity are ongoing areas of his work.

Daniel Mroczek, PhD, Professor of MSS and Psychology, examines the role of psychological factors, especially personality traits, in predicting health and longevity in midlife and older adulthood. As a lifespan developmental psychologist, he also studies how longitudinal changes in psychological factors influence health outcomes. He applies novel longitudinal modeling techniques to answer these questions and is involved in many long-term studies of aging that provide data across multiple decades.

Michael Newcomb, PhD, Research Assistant Professor (see Promoting Health Equity profile).

Cindy Nowinski, MD, PhD, Research Associate Professor, is an expert in health measurement with emphasis on patient-reported and performance-based outcomes. Her research focuses on the clinical use of these types of measures for improving health, healthcare quality and the management of chronic disease, particularly neurological disorders.

Tim Pearman, PhD, Associate Professor, directs the psychosocial oncology program of the Robert H. Lurie Comprehensive Cancer Center and collaborates on research focused on quality of life measurement and the science of psychosocial care to cancer survivors.

Frank Penedo, PhD, Roswell Park Professor and Director, Cancer Survivorship Institute of the Robert H. Lurie Comprehensive Cancer Center, (see Health Promotion & Disease Management profile).

Mitesh Rao, MD, Instructor (see Health Promotion and Disease Management profile).

continued on next page
Nan Rothrock, PhD, Research Associate Professor (see Health Measurement and Application profile).

John Salsman, PhD, Research Assistant Professor, examines how people “bounce back” and even thrive, despite significant health threats, such as cancer. In an era of personalized medicine, the goal of this work is to use empirical knowledge about healthy adaptation to illness to optimize and tailor supportive care programs for cancer survivors.

Benjamin Schalet, PhD, Research Assistant Professor (see Training the Next Generation profile).

Shiv Darius Tandon, PhD, Associate Professor (see Promoting Health Equity profile).

David Victorson, PhD, Associate Professor (see Training the Next Generation profile).

Joel Voss, PhD, Assistant Professor (see Mechanisms of Health and Disease profile).

Lynne Wagner, PhD, Associate Professor, studies the effects of cancer and treatment on health-related quality of life in cancer survivors. She is particularly interested in the use of evidence-based psychosocial and e-health treatments for anxiety, depression and symptom management in cancer survivors.

Betina Yanez, PhD, Assistant Professor (see Training the Next Generation profile).

Susan Yount, PhD, Associate Professor (see Health Promotion & Disease Management profile).

Lauren Wakschlag, PhD, Professor and Vice Chair for Scientific and Faculty Development, (see Mechanisms of Health & Disease profile).
## Secondary Faculty

<table>
<thead>
<tr>
<th>Last Name</th>
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<tr>
<td>Ackermann</td>
<td>Ronald</td>
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<td>Amy</td>
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“Describing the evidence that links healthy communities to better health outcomes must become part of the national and local narrative about health. Measurement provides the critical information for that narrative. Measuring health improvement processes and determinants with fidelity, and understanding their relationship to the nation’s well-being is critical. Standardization of measurement and a national population health measurement strategy are key aspects of galvanizing change in population health.”

Institute of Medicine’s 2010 Report—*For the Public’s Health: The Role of Measurement in Action and Accountability.*