Indiana University Five Year Self-Study Evaluation Report

April 15, 2021

Title: **Center for Enhancing Quality of Life in Chronic Illness**

Dates: **Original Center Funded:** 2000-2005; Extension 2005-2006

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Nursing is "the activities that promote health which occur in any caregiving situation."

Florence Nightingale, Notes on Nursing, 1860

A. Center Profile
A.1. Brief description of Center mission, including goals, history, and context

Mission and Goals. The Center for Enhancing Quality of Life in Chronic Illness (CEQL) is a school level center of the Indiana University School of Nursing (IUSON). The mission and goals of the center are presented in **Table 1**.

Table 1. Mission and Goals of CEQL 2016-2021 (revised 2016)

Mission	To build the science of quality of life in chronic illness by developing and testing high impact interventions.
Goal 1	Develop and test interventions to reduce symptoms, promote self-management, and improve quality of life among persons with chronic illness and family caregivers.
Goal 2	Translate efficacious and effective interventions to improve quality of care.
Goal 3	Integrate cutting-edge technologies across studies to build the science of quality of life in chronic illness research for the future.
Goal 4	Develop the next generation of nurse scientists to lead interdisciplinary teams in conducting high impact quality of life in chronic illness research.

History. CEQL was established in 2000 as a National Institute of Nursing Research (NINR) Center of Excellence (P30 NR05035, 2000-2005; Principal Investigator Joan K. Austin, PhD, RN, FAAN). The original mission and specific aims are presented in **Table 2**.

Table 2. Original Mission and Specific Aims (as written in NINR final progress report 2006)

Mission	The overall goal of CEQL was to advance knowledge related to improving the health-related quality of life of persons with chronic conditions across the life span.
Aim 1	Provide an infrastructure for collaborative research among scientists in nursing and other disciplines that will increase research on enhancing health-related quality of life in persons with chronic illness.
Aim 2	Prepare scientists in nursing and other health care disciplines through providing research training and technical support.
Aim 3	Support the development and testing of individualized interventions that will serve to increase appropriate coping and health behaviors and ultimately improve quality-of-life outcomes in persons with chronic conditions across the life span.

Note: In this report we use the term health-related quality of life as proposed in the original CEQL application. We acknowledge that the concepts health-related quality of life and quality of life have distinct yet overlapping definitions, theories, and measurement in scientific literature.

The **context** of the 1990s provided the rationale for the focus on the core outcome of health-related quality of life (HRQL) and the population of people with chronic illness. During the 1990s, there was growing recognition of the burden that chronic illness was placing on individuals and families, nurses and other health care professionals, health systems, and society. The rise in chronic illness was attributable to advanced medical therapies that improved survival of persons with chronic illnesses and an increased aging population. In addition to reducing mortality and morbidity, improving HRQL was recognized as a major patient-centered outcome that was central to people living with chronic illnesses and their families. At the same time, exciting scientific developments were occurring in the area of HRQL. New theories were developed to advance the science of HRQL[1-3] and new instruments were developed to measure it.[3-5] At the national level, there was a pressing need for new knowledge about interventions to improve HRQL among people with chronic illness. In 2021, HRQL remains a major patient-centered outcome for persons with serious chronic illness and is the focus of nursing and medical research.[6] The number of people living with serious chronic

illnesses (e.g., Alzheimer disease, cancer, epilepsy, heart failure) continues to rise, and enhancing HRQL is central to their wellbeing and survival.

As a discipline, nursing is uniquely positioned to focus on improving the HRQL of people with chronic illness through practice and research.[7,8] From the beginning of modern nursing as described by Florence Nightingale,[9] nurses have cared for the whole person and recognized that people are in transaction with their environment. In 2000, the IUSON was well positioned for a center of excellence focused on HRQL in chronic illness. The School had a solid cadre of mid-career and senior nurse researchers studying HRQL in chronic illness who were externally funded and leading interdisciplinary research teams. The School had a solid cadre of early career researchers studying health problems among patients with chronic illness, and these researchers needed mentoring, training, and support to advance their programs of research. Thus, the public health needs of the 1990s and the strength of IUSON faculty were aligned when NINR issued a call for centers of excellence.

Under the leadership of Dr. Joan Austin and Core Directors Drs. Victoria Champion and Susan Perkins, the aims were met of the NINR-funded CEQL. In **Table 3**, a summary is presented of major accomplishments (NINR progress report by Dr. Austin in 2006).

Table 3. Summary of Major Accomplishments of CEQL 2000-2005

Aim 1	Provide an infrastructure for collaborative research among scientists in nursing and other disciplines that will increase research on enhancing HRQL in persons with chronic illness. **Major accomplishments** • 16 nurse investigators received funding from CEQL Pilot Study Program • 13 of the 16 investigators received external funding for their research • 7 of the 16 investigators received NIH funding (3 R01s; 2 R15s; 1 K01; 1 R21) • 1995-2005 Indiana University School of Nursing external research funding increased 600% from $799,974 in 1995 to $4,876,318 (2004-2005) • "IUSON has emerged as a research-intensive nursing school" (Austin, 2006)
Aim 2	Prepare scientists in nursing and other health care disciplines through providing research training and technical support. **Major accomplishments** • Structured research programming on substantive content and research methods • Annual grant-writing workshop for faculty
Aim 3	Support the development and testing of individualized interventions that will serve to increase appropriate coping and health behaviors and ultimately improve quality-of-life outcomes in persons with chronic conditions across the life span. **Major accomplishments** • Substantial progress was made in developing and testing individualized interventions to improve coping and health behaviors to improve quality of life in chronic illness • Development and elaboration of quality-of-life research framework to guide pilot studies • As of 2006, 40 manuscripts were published or accepted for publication from 15 investigators

Indiana University Emerita Dean Angela McBride's visionary leadership was responsible for sustaining CEQL. She used three strategies to sustain CEQL (personal communication, 2018). First, Dean McBride planned for the generous endowment ($1.9 million) from the late Ms. Sally Reahard and family and other donors and the Indiana University (IU) Faculty Endowment Match Program. Second, she established the Sally Reahard Endowed Chair for the Director of CEQL. Third, she established the Mary and John Barron Quality of Life Investigator Research Fund Award endowed by the McBride family to support an annual award of $2,500 for HRQL research. Consequently, CEQL is one of the oldest centers of excellence in nursing in the United States.[10]

After NINR funding ended, Dr. Austin continued as the CEQL Director until her retirement in 2008. Subsequent CEQL Directors were Drs. Tamilyn Bakas (interim, 2008-2010), Janet Carpenter (2011-2015), and Susan Pressler (2015-present). From 2007 through 2015, CEQL funds continued to support pilot studies and CEQL aims were met.

In 2015, Dr. Pressler was appointed Professor, Sally Reahard Endowed Chair and Director of CEQL (Biosketch **Appendix A**). Dr. Pressler has a long record of sustained funding to investigate the HRQL among persons with heart failure. She was an early recipient of CEQL funding (2001) and the beneficiary of CEQL training. Upon becoming Director, Dr. Pressler worked closely with Dr. Janet Carpenter, Associate Dean of Research (Biosketch **Appendix A**), to evaluate CEQL and continue its activities. Dr. Pressler (1) established an advisory board to evaluate ongoing progress of CEQL in accomplishing mission and goals; (2) led revision of the mission and goals to ensure alignment with national priorities[11-13] (**Table 1**); (3) continued the priority goal of funding pilot studies; (4) coordinated training programs; and (5) maintained the financial health of CEQL.

A.2. Overview of projects undertaken and services offered by the Center

Overview of projects. The main projects undertaken by CEQL from 2015 through 2020 were (1) funding of pilot study projects, (2) leading training programs for CEQL investigators, other IUSON faculty, T32 fellows, and students, and (3) fundraising to support the CEQL endowment. Eleven pilot projects were funded to nine investigators (two investigators funded for two projects). Training programs included eleven CEQL visiting scholar presentations and five annual training day programs. Two celebration events were organized by CEQL. A gala was held in 2016 to celebrate 15 years of CEQL and 20 years of the IUSON NINR-funded T32 (T32 NR07066 Training in Behavioral Nursing). A virtual program was held in 2020 to celebrate 20 years of CEQL and Dr. Joan Austin's contributions and accomplishments to IUSON and NIH.

Overview of services. The research support services are outstanding at the IUSON. The services are available to faculty from CEQL and the IUSON Office of Research Support. During preparation of CEQL applications, faculty have assistance in (1) conceptualization and critique of draft applications, (2) statistical and design consultation, and (3) budget preparation. Drs. Pressler and Carpenter are available to review applications prior to submission. Dr. Susan Perkins (biosketch **Appendix A**) has 20% effort devoted to leading the IUSON Office of Research Support part-time biostatistics group and consults with faculty about research design and statistical analyses. She oversees a 20% data manager and a 20% master's prepared statistician to assist faculty. Budget preparation support is provided by Office of Research Support staff.

All CEQL applications are competitively reviewed and scored by IUSON faculty under direction of the faculty governance Research and Scholarly Advisory Committee, with Dr. Carpenter as Administrative Liaison to the Committee and Dr. Pressler as standing member in her role as CEQL Director. Final award approval is made by Dean Newhouse (biosketch **Appendix A**). After funding and throughout the duration of the award, Dr. Pressler and Mr. Richard Griffin, Program Manager, meet regularly with investigators to monitor progress and budget and address needed support. After data collection is completed, biostatistical support and editing services are available to assist with analyses and manuscript preparation.

Specific information is provided in **Section B. Center Quality and Viability** about projects and services.

A.3. Overview of faculty, staff, and other stakeholders involved in the Center, including demographics, qualifications, type of appointment, and principal contributions to Center mission, projects, and services

Drs. Susan Pressler and Janet Carpenter are the main faculty involved in CEQL. Dr. Pressler is responsible for all CEQL activities and accomplishments, including pilot studies,

training programs, and financial management. Dr. Pressler works closely with Dr. Carpenter who is responsible for the research activities and accomplishments across IUSON. Dean Newhouse is ultimately responsible for setting the vision for IUSON programs and outcomes. The IUSON faculty funded by CEQL are stakeholders (information presented in **Section B**).

Mr. Griffin, Program Manager, assists Dr. Pressler in the strategic direction, leadership, and operational activities of CEQL. He works closely with funded investigators in management of studies. Mr. Griffin coordinates training programs. He works closely with Dr. Pressler in managing the CEQL budget. Ms. Barbara Saligoe, Administrative Assistant for CEQL, provides general administrative support to Dr. Pressler and Mr. Griffin. For example, she assists in arrangements for CEQL meetings and programs.

Advisory board members were selected based on their expertise and leadership in substantive areas of HRQL, chronic illness, and biobehavioral science, methodologies, and training. Board members meet bi-annually to evaluate progress of CEQL. Names, qualifications, type of appointments, and principal contributions to CEQL are presented in **Table 4**.

Table 4. Faculty, Staff, and Advisory Board Members 2016-2020

Name, Qualifications	Type of Appointment	Contributions to CEQL
Susan J. Pressler PhD, RN, FAHA, FAAN	Professor, Sally Reahard Endowed Chair, CEQL Director	Overall responsibility for CEQL activities and accomplishments
Janet S. Carpenter PhD, RN, FAAN	Distinguished Professor, Audrey Geisel Endowed Chair, Associate Dean of Research	Associate Dean of Research Past CEQL Director
Robin P. Newhouse PhD, RN, FAAN	Distinguished Professor, Dean	Dean Advisory Board Member
Richard Griffin MS, BA	Program Manager	Assists in the strategic direction, leadership, and operational activities
Barbara Saligoe BSBA	Administrative Assistant	Provides general administrative support
Victoria L. Champion PhD, RN, FAAN	Distinguished Professor, Cullipher Endowed Chair Champion Center Director	Past CEQL Core Director Advisory Board Member
Susan G. Dorsey PhD, RN, FAAN University of Maryland	Professor and Chair, Pain and Translational Symptom Science, Co-Director, Center to Advance Chronic Pain Research	Advisory Board Member CEQL Co-Investigator, Visiting Scholar
Eileen D. Hacker PhD, RN FAAN	Professor, Chair of Science of Nursing Care	Austin CEQL Investigator Advisory Board Member
Miyeon Jung PhD, RN, FAHA	Assistant Professor, Community and Health Systems	Past CEQL Postdoctoral Fellow Advisory Board Member
Terry A. Lennie PhD, RN, FAHA, FAAN University of Kentucky	Marion E. McKenna Professor, Senior Associate Dean	Advisory Board Member Visiting Scholar
Wendy Miller PhD, RN, FAES, FAAN	Associate Professor, PhD Coordinator, T32 Co-Director	Past CEQL Investigator Advisory Board Member
Julie E. Otte PhD, RN, FAAN	Associate Professor, Assistant Dean of Evaluation	Past CEQL Investigator Advisory Board Member
Andrew Saykin Psy.D.	Raymond C. Beeler Professor of Radiology, Director, Indiana Alzheimer's Disease Center and Center for Neuroimaging	Advisory Board Member
Todd Skaar PhD	Professor of Medicine, Division of Clinical Pharmacology, Director, Indiana Institute for Personalized Medicine	Advisory Board Member

A.4. Overview of Center resources, including physical spaces, library holdings, support services available, and partnerships (campus, community, inter-institutional, and international) (Facilities and Resources Document)

Indiana University (IU), founded in Bloomington, Indiana in 1820, is one of the nation's premier research and educational institutions. IU began as a residential campus with a mission of teaching, research, and public service and grew into a family of eight campuses described by former President Thomas Ehrlich as "one university with eight front doors." The research core of the University is formed by the residential campus at Bloomington and the urban campus at Indianapolis. In fiscal year 2020, IU researchers received $854 million in external funding for research and related activities. IU has more than 200 research centers and institutes. Faculty and students on all campuses have access to many of the resources on other campuses. As a system, IU has over 114,000 students and over 5,000 full-time tenure/tenure track and non-tenure track faculty. It is one of the largest institutions of higher education in the United States. Over 1,800 degree-granting programs are offered by the various campuses. In 2018, over 21,000 degrees were awarded by IU across the state of Indiana.

Indiana University - Purdue University Indianapolis (IUPUI). The IU health professions schools of Nursing, Medicine, Health and Rehabilitation Sciences, Dentistry, and Public Health are located on the campus of IUPUI, a vibrant, innovative urban campus. Indianapolis is the third largest city in the Midwest and fifteenth largest in the United States. At IUPUI, more than 350 undergraduate, graduate, and professional academic programs are offered in 18 schools taught by more than 2,598 full time tenure/tenure track and non-tenure track faculty members to over 30,000 students (~22,500 undergraduate and ~8,100 graduate and doctoral students). According to the most recent annual report, external research funding during 2020 exceeded $630 million for the campus as a whole. IUPUI is accredited by the North Central Association of Colleges and Schools.

Indiana University School of Nursing (IUSON) has a rich history of education and research training. The School was founded in 1914 as the Indiana University Training School for Nurses and is located on the IUPUI campus in Indianapolis, Indiana. It offers the full range of degrees (BSN, MSN, DNP, and PhD) and postdoctoral research training with two National Institutes of Health (NIH) T32 funded programs. Robin Newhouse, PhD, RN, FAAN is Distinguished Professor and Dean of IUSON. Dean Newhouse is an internationally renowned scientist for her research in health system interventions to improve care processes and outcomes**.** Dean Newhouse has methodological expertise in clinical and pragmatic research approaches, including comparative effectiveness research. The resources at IUSON are outstanding. In 2020, IUSON ranked 10th among nursing schools at public universities and 16th among all nursing schools in funding from the NIH. Total research funding from external agencies to IUSON in fiscal year 2020 totaled $4,543,876 million.

Physical space. The four-story School of Nursing building at IUPUI provides space for all of the nursing programs. Administrative and Academic Affairs personnel and the Office of Lifelong Learning are housed on the first floor, which contains several classrooms and a 200-seat multi-media auditorium. The second floor contains 35 classrooms with seating capacity from 15 to 60. The third floor houses the department of Learning Resources and Resource Center for Innovation in Clinical Nursing Education; a computer cluster; a learning laboratory; an interactive video classroom for distance-learning courses; the Office of Research Support, and space designated for the T32 administrative office suite. Faculty offices and conference rooms are located on the fourth floor. Dr. Pressler's and CEQL investigators' offices are located on the fourth floor. Mr. Griffin's and Ms. Saligoe's offices are located in the Office of Research Support. Space is located on the third floor and in the basement of the Nursing building for project managers and research assistants. In 2016, IUSON converted office space into a neuropsychological testing room and a room with a phlebotomy station for faculty research. The testing room and station provided space for CEQL investigator Dr. Von Ah's pilot study.

Library holdings. The IUSON is served by two libraries, the IUPUI University Library and the IU Ruth Lilly Medical Library. Jointly, the libraries subscribe to or have access to approximately 5,000 electronic full-text journals, 800 online books, and 100 online databases covering medicine and nursing. Faculty members have access to the extensive resources of the other four IUPUI libraries and libraries across the eight IU campuses.

Support services. CEQL investigators have access to comprehensive services of IU and IUPUI to support their studies. Examples of services are presented in this section.

Indiana Clinical and Translational Sciences Institute. In 2018, IUPUI was awarded a second renewal from NIH for the Indiana Clinical and Translational Sciences Institute (I-CTSI) at Indiana University, with Purdue University, University of Notre Dame and other statewide partners. The I-CTSI is an invaluable resource to faculty as it offers access to project development teams, pilot grants, and core facilities. The mission of the I-CTSI is to increase translational biomedical research and improve the health of people of Indiana and beyond. The overall goal of the institute is to transform participating institutions to create an environment that facilitates the conduct of clinical and translational science research. History – Indiana CTSI

Indiana Clinical and Translational Sciences Institute Specimen Storage Facility (I-CTSI SSF) (Biorepository). The I-CTSI SSF is a state-of-the-art facility providing controlled access and monitored space with capacity for 60 mechanical freezers, liquid nitrogen storage for 300,000 specimens, and a specimen processing laboratory.

Indiana CTSI Clinical and Translational Support Laboratory. The Clinical and Translational Support Lab (CTSL) supports laboratory processing across the CTSI and partner institutions. The mission of the lab is to provide a central service that will benefit clinical and translational studies by offering cost efficient processing services and providing consistent quality and sample integrity. The CTSL serves the clinical and translational community by providing protocol processing set up, label design, and blood collection kit preparation, protocol specific blood and body fluid processing, specimen dispatch services, short-term storage (long term storage available through the Specimen Storage Facility), and facility/ equipment oversight and maintenance for the secondary processing lab.

Indiana Biobank. Established in 2010, the Indiana Biobank is intended to serve as a resource for scientists to have access to blood and tissue samples, along with patient health information, located in a single place.

IU Center for Diabetes and Metabolic Diseases. This Center provides Research Cores, Pilot and Feasibility funding, and Enrichment activities in support of diabetes and metabolic research at IU School of Medicine. The Analyte Laboratory is a fully equipped facility for metabolic phenotyping, measurements of blood analytes, maintenance of a biobank of human tissues and serum, and a host of specialized and customizable services.

IU Center for Medical Genomics. The goal of the Center for Medical Genomics at the IU School of Medicine is to improve health by facilitating cutting-edge research with state-of-the-art genomic technologies for studying gene expression and genetics. Advances in the human genome project provide the foundation for a new way of studying health and disease, in which differences in the sequence and expression of thousands of genes can be analyzed. The Center for Medical Genomics provides infrastructure and consulting for use of genomic technology in studies of disease and other biomedical research.

Partnerships (campus, community, inter-institutional and international)

Campus partnerships. Centers/Institutes There are over 100 research institutes, centers, laboratories, and specialized programs on the IUPUI campus and over 200 at IU. CEQL investigators have collaborated with the following health-related research groups: Krannert Institute of Cardiology, Indiana Alzheimer Disease Center, IU Simon Cancer Center, Regenstrief Institute, Diabetes Research and Training Center, Center for Excellence in Women's Health, Wells Center for Pediatric Research, Center for Research in Palliative and End-of-Life Communication and Training, and IU Center for Bioethics.

       Clinical partnerships. There are rich clinical facilities in Indianapolis and surrounding areas. Indiana University Health (IUH) system is Indiana's most comprehensive healthcare system, encompassing 3,707 physicians and 29,395 full-time employees working at over 100 locations across Indiana. Two IUH hospitals, Eskenazi Hospital, and Roudebush Veterans Affairs Medical Center are on the IUPUI campus and one IUH hospital is within two miles.

       Nursing partnership. Alpha Chapter of Sigma Theta Tau International Honor Society for Nursing (Sigma) is located at IUSON. Sigma was founded by six nursing students at Indiana University Nurses Training School in 1922. The Sigma headquarters is located adjacent to the IUPUI campus and provides library resources for scholarship, including the Virginia Henderson Library, which has access to a comprehensive database and nursing journals. Two CEQL training programs were held at Sigma. Six IUSON faculty members have been inducted into the Sigma Nurse Researcher Hall of Fame.

A.5. Any additional information needed to understand Center. No additional information.

B. Center Quality and Viability
B.1. Principal activities and accomplishments of the Center over the past five years, including discussion of evidence of quality/effectiveness of activities/accomplishments
       The CEQL pilot study activities are presented for 2015 to 2020 in **Table 5.** The CEQL training program activities are presented for 2015 to 2020 in **Table 6**.

Table 5. Investigators, Project Titles, Dates, and Funding 2015-2020

Name	Project Title	Project Dates	Funding
Janet Welch, PhD, RN, FAAN	*Understanding the Care Seeking Behaviors of People with Chronic Kidney Disease*	07/01/2015-06/30/2017	$8,966
Sheri Robb, PhD, MT-BC	*Active Music Engagement to Manage Acute Distress and Improve Positive Health Outcomes in Young Children Undergoing HSCT and Parents*	06/30/2015-10/31/2020	$45,598
Wendy Miller, PhD, RN, FAAN, FAES	*Pilot and Feasibility Testing of the Telephone Assessment and Problem Solving (TAPS) Intervention in Older Adults with Epilepsy*	07/01/2015-06/30/2017	$45,899
Rebecca Ellis, PhD, RN	*Patients' Perceptions of Healthcare Provider Communication and Understanding of Prescribed Medications*	07/01/2015-06/30/2017	$4,673
Miyeon Jung, PhD, RN, FAHA (Postdoctoral)	*Feasibility study: Development of Natural Restorative Environment Intervention with Virtual Reality to Improve Attention*	01/01/2016-12/31/2016	$42,840 Stipend $1000 Travel $8000 Research
Rebecca Ellis, PhD, RN	*Development of InterACT-Intervention to Promote Medication Adherence and Blood Pressure Control in Chronic Kidney Disease*	10/1/2016-09/30/2017	$50,000 CEQL $25,000 IU Vice Pres. Research
Diane Von Ah, PhD, RN, FAAN	*Home Based Cognitive Training Program for Breast Cancer Survivors Study*	07/01/2017-06/30/2018	$25,000 CEQL $25,000 IUSON $34,240 Bioimag.
Chen Xiao Chen, PhD, RN	*Phenotypic Characterization of Dysmenorrhea in Female Adolescents and Young Adults*	07/02/2018-Present	$50,000
Eileen Hacker, PhD, RN, FAAN	*Phenotypic Characterization of Persistent Fatigue in Allogeneic Hematopoietic Cell Transplantation Survivors*	07/01/2019-Present	$50,000
Kelly Wierenga, PhD, RN, FAHA	*Emotion Regulation Intervention to Sustain Physical Activity in Rural-Dwelling Women and Men after Myocardial Infarction*	07/01/2019-Present	$50,000 CEQL $10,000 Jonas Center/STTI

Kelly Wierenga, PhD, RN, FAHA	*Predictors of COVID-19 Self-management and Quality of Life among US Adults*	07/01/2019-Present	$6,000
IUSON faculty	CEQL funds not used; Reassigned funds	07/02/2020	$50,000

Table 6. Presenters, Program Type, Titles, Dates, Attendees 2015-2020

Presenter(s)	Type	Title	Date	Attendees
Nir Menachemi, PhD IU Fairbanks School of Public Health	Seminar	*Use of Foreign-educated Nurses and Patient Satisfaction in US Hospitals*	02/02/16	9
Jane Kapustin, PhD, RN AstraZeneca Pharmaceuticals	Seminar	*Diabetes Mellitus: Clinical Outcomes and Strategic Areas of Research*	03/30/16	20
Misook Chung, PhD, RN, FAHA, FAAN Terry Lennie, PhD, RN, FAHA, FAAN Debra Moser, PhD, RN, FAHA, FAAN University of Kentucky College of Nursing	Training Day	*Conducting High Impact Research through Collaboration*	05/25/16	17
Robin Newhouse, PhD, RN, FAAN Joan Austin, PhD, RN, FAAN IUSON	Training Day	*Implementation Science and Systems Research* and *NIH Common Data Elements*	08/30/16	30
Moira Visovatti, PhD, RN University of Michigan School of Nursing	Seminar	*Integrating Biomarkers into Cancer Nursing Research*	11/02/16	23
Christopher Lee, PhD, RN, FAHA, FAAN, FHSA Boston College School of Nursing	Training Day	*Statistical Methods and Consultations in Cardiovascular Areas* and Individual consultations	05/18/17	19
Liana Apostolova, MS, MD, FAAN (Neurology) Indiana Alzheimer's Disease Center	Seminar	*Symptom Science of Cognition*	01/09/18	20
Peter Pang, MD, MPH, FACC Department of Emergency Medicine, Indiana University School of Medicine	Seminar	*Community Outreach and Resource Efficiency Mobile Integrated Health*	02/06/18	16
Susan Pressler, PhD, RN, FAHA, FAAN Janet Carpenter, PhD, RN, FAAN Victoria Champion, PhD, RN, FAAN IUSON	Training Day	*Conducting Great Intervention Research*	05/15/18	15
Daniel Clark, PhD IU Center for Aging Research	Seminar	*Cognitive and Aerobic Resilience for the Brain*	11/02/18	15
Victoria Dickson, PhD, RN, FAHA, FHSA, FAAN New York University Rory Meyer College of Nursing	Seminar	*Cardiovascular Health Disparities in Special Populations* and Individual consultations	03/19/19	17
Lisa Kitko, PhD, RN, FAHA, FAAN Pennsylvania State College of Nursing	Seminar	*Palliative Care in Heart Failure: Challenges and Opportunities* and Individual consultations	04/02/19	13

Susan Pressler, PhD, RN, FAHA, FAAN Amy Knopf, PhD, MPH, RN, FAAN Susan Rawl, PhD, RN, FAAN Ukamaka Oruche, PhD, RN, FAAN Carol Shieh, DNSc, RN, FAAN IUSON	Training Day	*Addressing Health Equity in Research*	05/15/19	23
Betty Bekemeier, PhD, MPH, RN, FAAN University of Washington School of Nursing	Seminar	*Prevention Systems: Examining health outcomes associated with public health services and systems* and Presentation to T32 fellows	09/25/19	14
Susan G. Dorsey, PhD, RN, FAAN University of Maryland School of Nursing Joan K. Austin, PhD, RN, FAAN IUSON	Training Day	*Integrating Multiomics in Research* and *Research Training Across the Career Spectrum*	10/28/20	35

Additional Activities Information. The Mary and John Barron Quality of Life Award is administered as part of the CEQL activities. The $2,500 award is to support research expenses related to studies about HRQL. Recent recipients were Drs. Sheri Robb (2015), Yvonne Lu (2016), Ukamaka Oruche (2017), Chen X. Chen (2018), and Wendy Miller (2019).

A valuable service offered to CEQL investigators is support for external mentoring and mentoring teams. For example, CEQL supported a one-day mentoring team meeting for Dr. Rebecca Ellis. External researchers in medication adherence reviewed Dr. Ellis' work and met with her to evaluate and critique her research and discuss future directions. Mentoring team members were: (1) Jacqueline Dunbar-Jacobs, PhD, RN, FAAN, Distinguished Service Professor and Dean, University of Pittsburgh School of Nursing; (2) Kathleen Hickey, EdD, RN, FAAN, FAHA, Professor, Columbia University; (3) Todd Ruppar, PhD, RN, FAAN, FAHA, John L. and Helen Kellogg Professor of Nursing, Rush University; and (4) Cynthia Lippincott, PhD, RN, FAAN, University of Missouri, Kansas City. Dr. Ellis subsequently submitted R01 and R21 applications. A revision of the R21 is now under review. A product of Dr. Ellis' CEQL funding was development and testing of a smart pillbox. Dr. Ellis and her team received a US patent for their smart pillbox. She is the first nurse in the IUSON history to be awarded a patent.

In 2017, CEQL Director Pressler and Investigators Drs. Carol Shieh, Sheri Robb, Rebecca Ellis, and Wendy Miller presented a competitively selected symposium at the Midwest Nursing Research Society titled "Strategies for Building Self-management Interventions across High-risk Populations to Improve Health Outcomes." In 2018, Dr. Pressler presented an invited poster at the NINR Center Directors and T32 Directors that highlighted the history, accomplishments, and sustainability of CEQL.[10]

A unique opportunity offered to IUSON faculty by CEQL was a one-time, special award focused on research related to the coronavirus 2019 (COVID-19) pandemic. The pandemic began in Indiana on approximately March 6, 2020. March was the "early days" of the pandemic – we knew little about how devastating the pandemic would be or how long it would last. Drs. Wierenga and Pressler were brainstorming from their home offices what nurse researchers could do to help people cope with the pandemic. We proposed the idea of a special call for a CEQL COVID-19 grant to Dr. Carpenter who supported it. We used a small amount of existing unencumbered funds for the competitive call for applications ($6000). The award was made to Dr. Wierenga, who with colleagues conducted an innovative study in which they recruited 1380 participants to examine self-management behaviors and quality of life among people in the U.S. during the early days of the pandemic. They expanded the study and as of March 9, 2021 had conducted four follow-up surveys among a subsample (N=598) of the original participants.

Accomplishments. The CEQL accomplishments from 2015 to 2020 are summarized in **Table 7**. Evidence of quality is evaluated annually by the CEQL Director, staff, advisory board members, and Dr. Carpenter. CEQL investigators report publications, presentations, and future funding in our annual report. As of March 12, 2021, CEQL investigators had produced 23 peer-reviewed publications, delivered 21 peer-reviewed presentations, and received seven external research grants totaling $2,568,994 (2015-2020). Abstracts are presented of all funded pilot studies from 2000 to 2020 in **Appendix B.** Selected publications are presented in **Appendix C**.

Table 7. Accomplishments over the Past Five Years 2015-2020

Goal 1. Develop and test interventions to reduce symptoms, promote self-management, and improve quality of life among persons with chronic illness and family caregivers.
Accomplishments
9 investigators funded for 11 pilot studies
5 investigators received 7 externally funded grants for their research
3 investigators received NIH funding; 4 others submitted NIH applications and will be re-submitting
5 investigators received the Barron Award funds to support research activities
2 investigators obtained additional funds to expand pilot studies
• Dr. Ellis received $25,000 from Office of the Vice President for Research
• Dr. Von Ah received $34,240 from IU Biomedical Imaging Support Program
23 peer-reviewed publications
21 peer-reviewed presentations
Presented CEQL symposium at Midwest Nursing Research Society 2017 (Drs. Ellis; Miller; Pressler; Robb; Shieh)
Raised $18,061 for the CEQL endowment
Goal 2. Translate efficacious and effective interventions to improve quality of care.
Accomplishments
Disseminated bi-annual newsletter to highlight activities to faculty, alumni, and community
Goal 3. Integrate cutting-edge technologies across studies to build the science of quality of life in chronic illness research for the future.
Accomplishments
Cutting-edge technologies were incorporated into the CEQL pilot studies
• R. Ellis designed and tested an electronic pillbox to improve medication adherence among people with chronic kidney disease and hypertension
• D. Von Ah pilot tested computerized cognitive training intervention to improve cognitive functioning among women breast cancer survivors
• K. Wierenga built and is testing a mobile application to deliver a theoretically based emotion regulation intervention to decrease depression after myocardial infarction
• K. Wierenga developed a longitudinal study to evaluate self-management behaviors and quality of life during COVID-19 pandemic among people recruited using social media
• M. Jung built and tested prototype of virtual reality program to deliver theoretically based natural restorative environment intervention to improve cognition and HRQL in heart failure
Goal 4. Develop the next generation of nurse scientists to lead interdisciplinary teams in conducting high impact quality of life in chronic illness research.
Accomplishments
11 visiting scholars presented research seminars
5 annual training days were held
Established the Austin CEQL Scholar Program in 2020 to honor contributions of Dr. Austin
Funded 1 postdoctoral fellow for 1 year in 2016 (Dr. Miyeon Jung)
Funding approved by Dean and encumbered for 1 postdoctoral fellow for 2 years (2021-2023)

The **vitality** of CEQL is demonstrated by our most recent training program held on October 28, 2020 and we would like to highlight it here. Two stellar speakers presented to IUSON faculty and T32 fellows. The first speaker was Susan G. Dorsey, PhD, RN, FAAN, Professor, Pain and Translational Symptom Science and Co-Director of Center to Advance

Chronic Pain Research at University of Maryland School of Nursing. Dr. Dorsey's presentation "*Integrating Multiomics in Research*" was exciting and provided attendees with cutting-edge information.[13] She detailed methods that researchers can use to build rigorous studies that integrate multiomics, particularly genetics and genomics, to answer important research questions. Dr. Dorsey provided advice about how to begin to build a program of research that incorporates multiomics to deepen understanding of symptoms like pain that diminish HRQL for people with acute and chronic health conditions.

The second speaker was Joan Austin, PhD, RN, FAAN, Professor Emerita, IUSON. Dr. Austin presented "*Research Training across the Career Spectrum.*" In this engaging presentation, Dr. Austin traced her career from assistant professor to senior scientist studying children with epilepsy and their families. She skillfully wove together the methods she used to maintain scientific rigor of studies and the practical strategies she used to sustain her career.[14]

We then celebrated twenty years of CEQL and the contributions of Dr. Austin. Two of Dr. Austin's many contributions to IUSON were receiving the NINR funds to build CEQL and serving as the first Center Director. We were honored to have in attendance IU Emerita Dean Angela McBride and Patricia Grady, PhD, RN, FAAN, former Director of the NINR. Dean Emerita McBride gave remarks about Dr. Austin's contributions and introduced Dr. Grady. Dr. Grady worked closely with Dr. Austin for over 20 years. She provided remarks highlighting Dr. Austin's scientific contributions at the national level at NINR. Dr. Grady described Dr. Austin as the "consummate professional and a wonderful asset to the Institute and the nursing community."

Dean Robin Newhouse announced that in honor of Dr. Austin's contributions to IUSON, the faculty funded by CEQL in the future would be designated Austin CEQL Scholars. This designation will allow for ongoing recognition of Dr. Austin's contributions. At our grand finale, Dr. Janet Carpenter presented Dr. Austin with a beautiful, commissioned painting and accompanying artist's statement to commemorate the day.

B.2. Description of the units/collaborators/partners involved in the Center, including specific roles and contributions each makes to its functioning

The Director and CEQL-funded faculty members collaborate with a wide network of nursing and interdisciplinary colleagues across IUPUI and IU Bloomington campuses and other universities. For example, Dr. Eileen Hacker, is collaborating with the following colleagues on her CEQL pilot study: (1) Ukamaka Oruche, PhD, RN, FAAN, Associate Professor, IUSON, expertise in emotional distress; (2) Susan Perkins, PhD, Professor of Biostatistics, IU School of Medicine Department of Biostatistics and IUSON, expertise in biostatistics; (3) Susan J. Pressler, PhD, RN, FAAN, Professor, IUSON, expertise in cognitive function; and (4) Kelly Wierenga, PhD, RN, Assistant Professor, IUSON, expertise in impact of COVID-19 on health perceptions. In a second example, Dr. Kelly Wierenga collaborated with the following colleagues on the manuscript of results from the CEQL funded study about perceptions during COVID-19. Her co-authors were: (1) Scott Emory Moore, PhD, RN, Assistant Professor, Case Western Reserve University, France Payne Bolton School of Nursing, expertise is psychosocial factors and decision making; (2) Braveheart Gillani, PhD, Case Western Reserve University, Jack, Joseph and Morton Mandel School of Applied Social Sciences, expertise in racial equity and social justice; (3) Eileen Hacker, PhD, RN, FAAN, Professor, IUSON, expertise in self-management behaviors and quality of life; (4) Ms. Laura Janine Mintz, MetroHealth, primary care provider focused on health of sexual and gender minority populations; (5) Susan Perkins, PhD, Professor of Biostatistics, IU School of Medicine Department of Biostatistics and IUSON, expertise in complex and longitudinal biostatistics; (6) Dana M. Price, PhD, Case Western Reserve University, Jack, Joseph and Morton Mandel School of Applied Social Sciences, expertise in community- and system-based research with sexual and gender minority populations; and (7) Susan J. Pressler, PhD, RN, FAAN, Professor, IUSON, expertise in symptoms and HRQL.

B.3. Discussion of how the Center contributes to the educational, research, and service/engagement missions of the units/collaborators/partners involved in its functioning

CEQL contributes to the missions of other units and collaborators through the pilot studies conducted by the CEQL investigators and the CEQL training programs.

B.4. Analysis and summary of feedback from Center stakeholders, including how this feedback is used to improve the function of the Center

Evaluations are completed by attendees after each CEQL training program. Mr. Griffin summarizes the information for review by Drs. Pressler and Carpenter. Attendees are requested to rate the quality and focus of presentations and recommend future topics. For example, in 2016 faculty prioritized health disparities as a topic for a future program. Our 2017 training day focused on health equity in research. As a group, we viewed the keynote videopresentation from the Council for the Advancement of Nursing Science meeting titled "My Journey to Discover Why Health Disparities Exist" by Dr. Thomas Laviest (2016 State of the Science Congress - YouTube). We then had presentations from faculty (Drs. Rawl, Knopf, Oruche, and Shieh) and a discussion about health disparities in our own programs of research.

B.5. Discussion of the forecast of future demand for the Center projects, services, and activities, including how the Center is distinctive or differentiated from other similar providers

We anticipate that the demand for the Center's pilot projects, services, and activities will continue and expand. Enhancing HRQL in chronic illness remains a national priority, and national estimates are that chronic illness will continue to grow at an alarming rate. Moreover, we anticipate continued demand for CEQL because IUSON is a research-intensive school.

CEQL is distinctive because of its substantive foci on HRQL, serious chronic illness, biobehavioral research, and nursing science. To our knowledge, no other IU centers have these foci. It is uniquely positioned to support faculty from the IUSON in collaboration with researchers from across campuses and other universities.

B.6. Analysis of the fiscal health of the Center, including how well leaders manage budget resources, attract diverse and sustainable revenue streams to support the Center (highlight fundraising)

The Sally Reahard Teaching and Research Endowment was established in 2001, by a generous donation of $1.9 million dollars. The gift to the IUSON was to endow the Directorship of CEQL. The Directorship is funded by a calculated amount of interest income (per IU policy) from the Sally Reahard Teaching and Research Fund, plus funds allocated from IU and IUSON based on the IU Faculty Endowment Matching Program (**Table 8**).

The CEQL budget process is that the Director submits an annual budget for review and approval by the IUSON Dean. The annual budget supports a percentage of effort for the CEQL Director, Program Manager, and Administrative Assistant, travel expenses, visiting scholar fees and travel, and Investigator pilot funds. The annual budgets are presented for 2015-2020 in **Table 8**. Budget fluctuations are attributable to the amount of effort for the CEQL Director and amount of pilot funds awarded. The CEQL Director was funded by multiple external grants from 2015 to 2020 which allowed us to allocate more funds to pilot studies and a postdoctoral fellowship. The CEQL return on investment data are presented in **Figure 2**. The return on investment from 2015 to 2020 was nearly sixfold.

Fundraising was added as a CEQL goal in 2018. We set a target goal of $5,000 annually that would become part of the endowment. Donations received were $7,200 in 2018, $4,826 in 2019, and $6,035 in 2020 for a **total of $18,061**.

Table 8. Annual Budgets 2015-2020

Year	Sally Reahard Teaching and Research Endowment Book Value	Endowment Income	FEMP[a] IU Match	FEMP IUSON Match	Annual Operating Budget
FY 2015-16	$2,122,790	$95,846	$48,387	$48,387	$192,620
FY 2016-17	$2,128,168	$94,217	$48,387	$48,387	$215,991[b]
FY 2017-18	$2,127,582	$92,120	$48,387	$48,387	$188,894
FY 2018-19	$2,126,420	$93,831	$48,387	$48,387	$190,605
FY 2019-20	$2,124,830	$95,966	$48,387	$48,387	$192,740

[a]Faculty Endowment Matching Plan; [b]Vice Chancellor for Research added $25,000 Ellis study

Figure 1a. Return on Investment 2015-2020   **Figure 1b. Return on Investment 2000-2020**
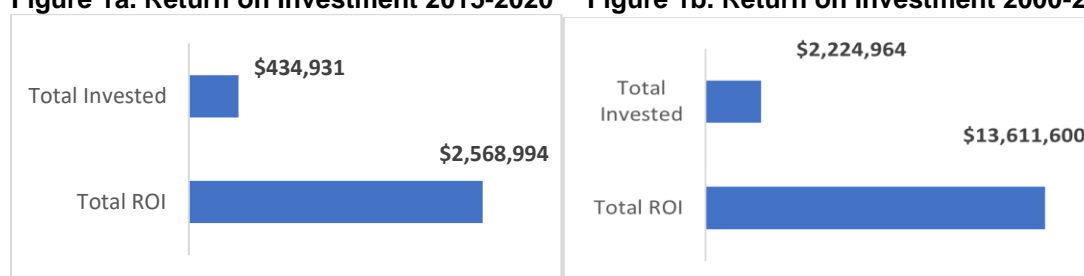
B.7. Assessment of the adequacy of facilities, including technology/specialized equipment used to support Center functioning.

The IUSON, IUPUI, and IU facilities are adequate to support CEQL functioning. Examples are provided below of facilities that supported CEQL researchers from 2015 to 2020.

Indiana University Computer/Statistical Services. Computer services are a strength at IU. University Information Technology Services (UITS), with offices on the Bloomington and Indianapolis campuses, is responsible for the continued development of a vision of excellence in research, teaching outreach, and lifelong learning. UITS is comprised of highly trained professionals with expertise that spans the field of information technology. UITS provides tools and services that support the academic and administrative work of the University. Computing tools include a variety of timesharing computers, hundreds of public-accesses, Internet-connected workstations, all equipped with current software, and a number of supercomputers.

IUPUI and IUSON Learning and Technology Support Services. IUPUI and IUSON provide support teams on the IUPUI campus to meet unique needs within the school. The range of technology supported by the IUSON team includes: audiovisual, web conferencing and videoconferencing support; desktop, laptop, and mobile device support; server and storage systems support; application development; simulation support; instructional design support; and faculty, staff and student training and development.

The IUSON maintains up-to-date hardware and software for use by faculty, staff, and students. In the Office of Research and Scholarship, an array of software/hardware exists to facilitate statistical analysis (Stat Power, SPSS, SAS, Stata), writing (EndNote), database management (REDCap), and dissemination of results (FrontPage, PowerPoint, Print Shop).

B.8. Assessment of human resources contributing to the Center, including talent recruitment, retention, diversity, and development/advancement priorities

The CEQL Director and staff work closely with the Office of Research Support staff within the IUSON to support faculty in the development and conduct of research to advance nursing science through expansion of external funding under the direction of Dr. Janet Carpenter, Associate Dean of Research. The Office of Research Support staff provide information about research resources, consultation about design and methods, statistical analysis, budget computations, and manuscript preparation. The staff offer pre- and post-award services, including review of application guidelines, budget preparation, assembly and official submission of applications, facilitation of project start-up work, and budget/project management training. The staff coordinates the experiences of research assistants, publicizes faculty and student research accomplishments, and facilitates joint projects between practitioners and educators. In partnership with the IU School of Medicine, a core of biostatisticians and data managers are available for consultation and collaboration across a broad range of analytical expertise. Research review groups and formal mentor and peer review systems are in place.

C. Center Strategic Priorities
C.1. Discussion of Center contributions to IUPUI's strategic plan

CEQL goals and accomplishments align with IUPUI and IUSON strategic plans. In the section below, the alignment is shown of the IUPUI Strategic Plan Priority and Goals, the IUSON Strategic Plan Focus Area and Goals, and the corresponding CEQL Goal(s).

IUPUI Strategic Plan Priority 2: Advances in Health and Life Sciences
Goal 5: Leverage our strengths in health and life sciences. Advance our capabilities and contributions through interdisciplinary efforts— often referred to as interprofessional education and collaborative practice—to improve the well-being of communities and tackle important public health challenges.
IUSON Strategic Plan Focus Area 3: Research
Goal 2: Strengthen portfolio of externally funded research to improve patient outcomes in Indiana, the nation, and the world.
Goal 3: Increase breadth and depth of research funding from sources that provide indirect funds.
Goal 4: Accelerate translation of research into practice and curriculum.
CEQL Goal 1: Develop and test interventions to reduce symptoms, promote self-management, and improve quality of life among persons with chronic illness and family caregivers.
CEQL Goal 2: Translate efficacious and effective interventions to improve quality of care.

IUPUI Strategic Plan Priority 3: Contributions to the Well-being of the Citizens of Indianapolis, the State of Indiana, and Beyond
Goal 6: Accelerate innovation, discovery, and creative activity. Enhance our capacity and support for research, scholarship, and creative activity to improve the quality of life, generate new knowledge, and fuel economic development.
IUSON Strategic Plan Focus Area 3: Research
Goal 2: Strengthen portfolio of externally funded research to improve patient outcomes in Indiana, the nation, and the world.
Goal 3: Increase breadth and depth of research funding from sources that provide indirect funds.
Goal 4: Accelerate translation of research into practice and curriculum.
CEQL Goal 3. Integrate cutting-edge technologies across studies to build the science of quality of life in chronic illness research for the future.

IUPUI Strategic Plan Priority 1: The Success of our Students
Goal 1: Promote Undergraduate Student Learning and Success
Goal 2: Increase Capacity for Graduate Education
IUPUI Strategic Plan Priority 3: Contributions to the Well-being of the Citizens of Indianapolis, the State of Indiana, and Beyond
Goal 10: Develop faculty and staff. Invest in and develop faculty and staff so that individuals realize their fullest potential to contribute to IUPUI's excellence and success.
IUSON Strategic Plan Focus Area 3: Research
Goal 2: Strengthen portfolio of externally funded research to improve patient outcomes in Indiana, the nation, and the world.
Goal 3: Increase breadth and depth of research funding from sources that provide indirect funds.
Goal 4: Accelerate translation of research into practice and curriculum.
CEQL Goal 4. Develop the next generation of nurse scientists to lead interdisciplinary teams in conducting high impact quality of life in chronic illness research.

C.2. A summary of the overall internal strengths and weaknesses of the Center and external opportunities and threats

Internal strengths: The internal strengths of CEQL are many. We organized strengths in this report into three areas: (1) faculty conducting research in HRQL and chronic illness; (2) financial strength; and (3) training. First, the IUSON faculty members are the most important internal strength. We have a solid cadre of early and fewer mid-career investigators who are conducting research in HRQL and chronic illness conditions and are eligible to apply for CEQL pilot funds. We have a cadre of senior nurse investigators who are available to collaborate with and mentor the early and mid-career investigators. We have many excellent interdisciplinary investigators and Centers across the IU campuses to collaborate with and mentor CEQL investigators. Second, the financial health of CEQL is an important internal strength. CEQL has ongoing support from the endowments, the IU Faculty Match Program, the IUSON Dean's office, Associate Dean for Research, and Office of Research Support staff. Third, the substantial amount of training provided to IUSON faculty is a strength.

Internal weaknesses: We identified three internal weaknesses of CEQL. The first weakness is the time it takes for investigators to complete sufficiently strong pilot studies and transition to major external funding. This issue is not unique to nursing research or IUSON, but we are mindful of the importance of helping investigators progress. We have addressed this weakness by increasing alignment of pilot studies with national research priorities (e.g., biobehavioral methods) and strengthening the rigor of pilot studies (e.g., larger sample sizes, stronger designs, more precise measurement of variables). We are considering other options that may address this issue (e.g., increased biostatistical support, innovative writing strategies such as Sprint method[15]). The second weakness is the need to better quantify the benefits and value that CEQL training adds to faculty and IUSON outcomes. One of our advisory board members noted several times that we probably "underestimate the value of training" supported by CEQL. The third weakness, noted at the beginning of the COVID-19 pandemic, was the need for us as nurse investigators to have a rapid response plan to address emerging public health crises in which nursing has a pivotal role to play. We addressed the pandemic by funding one pilot study. This area needs future attention because it directly impacts HRQL of society.

External opportunities: External opportunities are many for CEQL. At this time in CEQL's evolution, it seems that opportunities are tremendous if the IUSON and faculty choose to pursue them. We plan to continue funding pilot projects and coordinating training programs for IUSON faculty. At the CEQL Advisory Board meeting on November 24, 2020, members brainstormed possibilities for the future of CEQL. Ideas generated were:

1) Look for opportunities for innovation. Create products, patents, and copyrights. "Build innovations."
2) Consider "contemporary real-world issues like the pandemic" when thinking about the future. "Be responsive to heterogeneity, disparities, and real-world goals."
3) Nursing science needs to be "nimble" to issues that arise…"health systems move rapidly…science slowly" need to learn to do research quickly and "dig down deep."
4) "Develop new technologies to do easier patient-reported outcomes collection – databases with patient outcomes and electronic health records…patient genomics"
5) Develop as a national or international center to build HRQL research; could collaborate with other schools of nursing. Note: There is an International Society for Quality of Life – interdisciplinary (https://www.isoqol.org/who-we-are/).
6) Return on investment – can monies generated by funding based on CEQL pilot studies be returned to CEQL? We need a database of CEQL that can be shared at board meetings and used for future evaluation and projections.

External threats: A possible external threat to CEQL is competition with other Centers at IU and external to IU. We continue to address this threat by supporting IUSON faculty with substantial pilot funds and training programs. Another possible threat would be changes in the endowment or financial health of CEQL. We carefully manage the funds and have raised additional endowment funds to support the mission and goals. A third possible threat is the declining number of tenured/tenure-track faculty (down 50% in the past decade at IUSON), an issue being experienced at many nursing schools across the country. This threat is being addressed at the School level.

C.3. Discussion of the Center's Future Directions

CEQL is poised for a **bold** future. After twenty years of successful accomplishments, it is the ideal time to envision the next twenty years. In her book on leadership, IU Emerita Dean McBride proposes a schema for degrees of impact that is informative in planning CEQL's future. The highest level of impact is culture change in which new paradigms and models are discovered and new processes and products are developed.[16] Guided by the highest level of impact, we propose the following future directions for CEQL:

1. Develop CEQL as a nationally recognized center to build the science of HRQL in serious chronic illness and train the next generation of nurse scientists in this area. Specific strategies may include:
   a. Publish a scholarly article about CEQL accomplishments and future plans. A possible working title is "Center for Enhancing Quality of Life in Chronic Illness: Honoring the Past, Working for Today, Visioning the Future" with target journals *Nursing Outlook* or *Journal of Nursing Scholarship*;
   b. Publish a new theoretical framework of HRQL building on past research;[17-19]
   c. Develop a roadmap[20] for achieving the plan's goals consistent with IUPUI and IUSON strategic plans;
   d. Continue to fund high quality pilot studies that are disseminated in high impact journals and at major research conferences;
   e. Fund one postdoctoral fellowship every five to ten years; and
   f. Build a research data repository with harmonized HRQL data that could be used by investigators and PhD students and fellows.[21]

C.4. Specific questions (4-6) about which the Center leaders and colleagues seek guidance from the review team

1. What is the "right" balance of CEQL activities to lead it into the future while continuing to support IUSON faculty researchers?

2. What strategies could we use to become a leading nationally/internationally recognized center?
3. What strategies could we use to highlight and build upon CEQL's uniqueness as a center focused on nursing science?
4. What strategies could we use to strengthen our research portfolio?
5. Are there other fundraising goals and strategies that we should consider?
6. Re: budget – what is the "right" amount of funds for the annual operating budget?

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Appendix A.   Biosketches of Drs. Pressler, Carpenter, Perkins, Newhouse

BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors.
Follow this format for each person. **DO NOT EXCEED FIVE PAGES.**

NAME: Pressler, Susan, J.

eRA COMMONS USER NAME (credential, e.g., agency login): SBENNET

POSITION TITLE: Professor, Sally Reahard Endowed Chair, and Director, Center for Enhancing Quality of Life in Chronic Illness

EDUCATION/TRAINING *(Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.)*

INSTITUTION AND LOCATION	DEGREE *(if applicable)*	Completion Date MM/YYYY	FIELD OF STUDY
Indiana State University, Terre Haute, IN	BSN	05/1976	Nursing
Indiana University, Indianapolis, IN	MSN	05/1980	Nursing of Adults with Biodissonance/Administration
Indiana University, Indianapolis, IN	PhD	09/1990	Nursing Synthesis/Educational Psychology

A. Personal Statement

My program of research is focused on improving cognition, health-related quality of life (HRQL), and survival among patients with HF. I have received funding over the past 30 years to conduct studies to characterize the complex symptom of cognitive dysfunction in HF, determine predictors and consequences of this cognitive dysfunction, and test novel interventions to improve cognition, HRQL, and survival among patients with HF. I was Co-PI of a study to evaluate the best measurement of HRQL among 211 patients with HF (AHRQ R03HS90363; 1998-2001). I was PI of a comparative study (NINR R01NR008147; 2004-2008) to investigate cognitive deficits of 249 patients with HF, 63 healthy participants, and 102 patients with medical conditions but not HF. We identified memory loss as independent predictor of 12-month all-cause mortality. I was PI of two randomized controlled pilot studies (R01NR016116; P30NR009000; University of Michigan; 2008-2010; 2013-2014) (n=40; n=27) to test initial efficacy of the plasticity-based computerized cognitive training intervention BrainHQ to improve memory and serum brain-derived neurotrophic factor (BDNF) among patients with HF. I am MPI of the study "Cognitive Intervention to Improve Memory in Heart Failure Patients" (R01NR016116; 2016-2021), a three-arm randomized controlled trial to test the efficacy of a computerized cognitive training intervention to improve memory and HRQL and increase serum among 256 patients with HF. Data collection was completed in November 2020 and manuscripts are being written. My work has been widely disseminated in over 130 scientific publications including *Journal of Cardiac Failure, Heart and Lung, Journal of Cardiovascular Nursing,* and *Nursing Research: Heart Failure.* I have extensive experience in training researchers. I was PI and Program Director of "Effectiveness and Implementation Science for Health Promotion and Chronic Illness Care in Vulnerable Populations" (funded by Rita and Alex Hillman Foundation for $3M; 2012-2015) at University of Michigan School of Nursing. I served as Co-Director of two NINR-funded T32 grants (NINR T32 NR07066 "Training in Behavioral Nursing; 2006-2007 and NINR T32 NR018406; 2019-2021) at Indiana University. I am Director of the Center for Enhancing Quality of Life in Chronic Illness, an endowed Center that funds pilot studies and provides training for early and mid-career faculty at Indiana University School of Nursing.

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B. Positions and Honors
Positions and Employment
1979 – 1984 Instructor, Ball State University School of Nursing, Muncie, IN
1984 – 1990 Assistant Professor, Ball State University School of Nursing, Muncie, IN
1990 – 1994 Clinical Nurse Specialist, Indiana University (IU) Medical Center, Indianapolis, IN
1990 – 1996 Assistant Professor, IU School of Nursing, Indianapolis, IN
1996 – 2000 Associate Professor, IU School of Nursing, Indianapolis, IN
1997 – 2003 Research Consultant, Clarian Health Partners, Indianapolis, IN
1998 – 2007 Affiliated Scientist, IU Center for Aging Research, Indianapolis, IN
2000 – 2007 Professor, IU School of Nursing, Indianapolis, IN
2000 – 2007 Affiliated Scientist, IU Center for Enhancing Quality of Life in Chronic Illness, Indianapolis, IN
2005 – 2007 Co-Director, NINR T32 Training Grant for Health Behavior Research, IU School of Nursing, Indianapolis, IN
2007 – 2015 Professor, University of Michigan (UM) School of Nursing, Ann Arbor, MI
2011 – 2013 Associate Dean for Graduate Studies, UM School of Nursing, Ann Arbor, MI
2011 – 2014 PhD Program Director, UM School of Nursing, Ann Arbor, MI
2012 – 2014 Director, Hillman Scholars Program in Nursing Innovation, UM School of Nursing, Ann Arbor, MI
2015 - Professor, Sally Reahard Endowed Chair, and Director, Center for Enhancing Quality of Life in Chronic Illness, IU School of Nursing, Indianapolis, IN
2017 - 2017 Acting Associate Dean for Research, IU School of Nursing, Indianapolis, IN
2019 – Co-Director, NINR T32 Training Grant for Training in Advanced Self-Management Interventions for Serious Chronic Conditions, IU School of Nursing, Indianapolis, IN

Other Experience and Professional Memberships
2002 – 2008 Executive Council, Heart Failure Society of America, Member
2007 – 2009 American Heart Association Cardiovascular Nursing Council, Chair
2007 – 2012 Case Western Reserve University P30 SMART: Center of Excellence for Self-Management Advancement through Research and Translation, External Advisory Committee, Member
2012- 2017 American Council of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines, Member
2012 - 2017 Midwest Nursing Research Society Foundation Board, Trustee
2012- 2019 Case Western Reserve University P30 SMART Center II: Brain-Behavior Connections in Self-Management Science, External Advisory Committee, Member
2020 – Heart Failure Society of America, Scientific Statements Committee, Member

Honors
1999 Fellow of the Council on Cardiovascular Nursing, American Heart Association (AHA)
2003 Fellow of the American Academy of Nursing
2004 Prestigious External Award Recognition, Indiana University
2004 Indiana University Trustees' Teaching Award, Indiana University
2009 Top 10 Scientific and Clinical Advancements Award, AHA Cardiovascular Nursing Council
2013 Distinguished Visiting Research Fellow, Australian Catholic University, Melbourne, Australia
2013 International Invited Speaker, Cardiac Society of Australia and New Zealand Annual Meeting, Gold Coast, Australia
2013 Consultant for cognitive function measurement., SECRET: Study to Evaluate Changing REsponders to Therapy in Congestive Heart Failure Trial (The SECRET of CHF Trial) Cardiovascular Clinical Science Foundation
2014 Top 100 Alumni, Indiana University School of Nursing
2015 Katharine A. Lembright Award, Council on Cardiovascular and Stroke Nursing, AHA
2016 Maryanne Roehm Nursing Scholar Award, College of Health and Human Services, Indiana State University, Terre Haute, Indiana
2017 Kathleen Dracup Early Career Mentoring Award, Council on Cardiovascular and Stroke Nursing AHA

2018   Distinguished Achievement Award, Council on Cardiovascular and Stroke Nursing, AHA
2019   Indiana Women of Achievement Award, Ball State University, March 20, 2019

C. Contribution to Science

Memory loss is more frequent in patients with HF compared with healthy adults and patients with other medical conditions but not HF. Previously, it was unclear whether patients with HF had more cognitive deficits than persons without HF and whether these deficits were related to age or comorbidity. I was PI of an interdisciplinary team which conducted an NIH-funded comparative explanatory study. We found that 249 patients with HF had significantly more cognitive deficits compared with 63 healthy adults and 102 age- and education-matched patients with medical conditions but not HF. The most frequent deficits were memory loss (23%), psychomotor slowing (19%), and executive function (19%). More severe HF was associated with greater memory loss. In qualitative interviews, patients with HF and cognitive deficits reported emotional distress and loss of independence that diminished their quality of life. These results contributed to recognition that HF is associated with and may cause cognitive dysfunction, particularly memory loss, in HF. Recommendations to assess cognitive function in patients with HF are now part of Heart Failure Society of America's national practice guidelines and American Heart Association's scientific statement on HF self-care. I have presented this research at local, national, and international meetings.

   a. Sauvé MJ, Lewis WR, Blankenbiller M, Rickabaugh B, **Pressler SJ.** Cognitive impairments in chronic heart failure: A case controlled study. J Card Fail, 2009;15(1):1-10. PMID: 19181287.
   b. Sloan RS, **Pressler SJ**. Cognitive deficits in heart failure: Re-cognition of vulnerability as a strange new world. J Cardiovasc Nurs, 2009;24(3):241-8. PMID: 19390342.
   c. **Pressler SJ**, Subramanian U, Kareken D, Perkins SM, Gradus-Pizlo I, Sauvé MJ, Ding Y, Kim J, Sloan R, Jaynes H, Shaw RM. Cognitive deficits and health-related quality of life in chronic heart failure. J Cardiovasc Nurs, 2010;25(3):189-98. PMCID: PMC2922930.
   d. **Pressler SJ**, Subramanian U, Perkins SM, Gradus-Pizlo I, Kareken D, Kim J, Ding Y, Sauvé MJ, Sloan R. Measuring depressive symptoms in heart failure: validity and reliability of the patient health questionnaire-8. Am J Crit Care, 2011;20(2):146-52. PMID: 20378777.

Memory loss in HF is associated with 12-month all-cause mortality. In a substudy of the above R01, we followed 166 patients with HF over 12 months. The central finding was that baseline memory loss was a significant and independent predictor of 12-month all-cause mortality. A 1-unit increase in memory predicted a reduction in the odds of death by about a fourth. These results provide strong support for testing interventions to improve memory and prevent or delay memory loss in HF. My role was PI.

   a. **Pressler SJ,** Kim J, Riley P, Ronis DL, Gradus-Pizlo I. Memory dysfunction, psychomotor slowing, and decreased executive function predict mortality in patients with heart failure and low ejection fraction. J Card Fail, 2010;16(9):750-60. PMCID: PMC2929394.
   b. Chou C, **Pressler SJ**. Oxygen saturation is associated with memory performance in heart failure patients with sleep-disordered breathing risk. Western J Nurs Res, 2011;33(1):136-137.
   c. Gure TR, Blaum CS, Giordani B, Koelling TM, Galecki A, **Pressler SJ**, Hummel SL, Langa KM. Prevalence of cognitive impairment in older adults with heart failure. J Am Geriatr Soc, 2012;60(9):1724-9. PMCID: PMC3445700.
   d. Jung M, Jonides J, Northouse L, Berman MG, Koelling TM, **Pressler SJ**. Randomized crossover study of the Natural Restorative Environment Intervention to improve attention and mood in heart failure. J Cardiovasc Nurs, 2017;32(5):464-79. PMID: 27755225.

Computerized cognitive training intervention is efficacious in early studies among HF patients. I lead an interdisciplinary team and we have conducted one feasibility (n = 4) and two randomized controlled studies with positive results of the computerized cognitive training intervention, BrainHQ (formerly Brain Fitness) by Posit Science. In the first randomized controlled study "Nurse-Enhanced Memory Intervention in Heart Failure" (MEMOIR) (NR00814 and P30 NR009000), 40 patients were enrolled and 34 completed the 12-week study. Patients were randomly assigned to the computerized cognitive training intervention using Brain HQ and the active control health education intervention. The central finding was that compared with patients who received the active control health education group, patients who received BrainHQ had significantly improved delayed recall memory. In the second randomized controlled study among 27 patients, MEMOIR-2, the central finding was that compared with patients who received the active control intervention, patients who received BrainHQ

had significantly improved working memory and increased serum brain-derived neurotrophic factor (BDNF), a neurotrophin associated with neuronal growth, learning, and memory. Our team was the first to conduct studies of computerized cognitive training interventions using Brain HQ targeted at memory loss in HF and to measure serum BDNF as an outcome in HF. These studies were important scientifically because they demonstrated that memory loss in HF was amenable to intervention and tested serum BDNF as a potential biological measure of BrainHQ effect was exciting. My role was PI.

a. Hammers DB, Jung M, **Pressler SJ**, Sullivan BJ, Koelling T, Giordani B. Clinical utility of auditory memory testing in a heart failure population. J Cardiovasc Nurs, 2013;28(5):444-52. PMID: 22722475.
   b. **Pressler SJ,** Martineau A, Grossi J, Giordani B, Koelling TM, Ronis DL, Riley PL, Chou CC, Sullivan BJ, Smith DG. Healthcare resource use among heart failure patients in a randomized pilot study of a cognitive training intervention. Heart Lung, 2013;42(5):332-8. PMCID: PMC3781586.
   c. **Pressler SJ,** Titler M, Koelling TM, Riley PL, Jung M, Hoyland-Domenico L, Ronis DL, Smith DG, Bleske BE, Dorsey SG, Giordani B. Nurse-Enhanced Computerized Cognitive Training Increases Serum Brain-Derived Neurotropic Factor Levels and Improves Working Memory in Heart Failure. J Card Fail, 2015;21(8):630-41. PMID: 25982826.
   d. **Pressler SJ,** Harrison J, Titler M, Koelling TM, Jung M, Dorsey SG, Bakoyannis G, Riley PL, HoylandDomenico L, Giordani B. *APOE* ε4 and Memory among Patients with Heart Failure. West J Nurs Res, 2017;39(4):455-472. PMID: 27733670.

Complete List of Published Work in My Bibliography:
http://www.ncbi.nlm.nih.gov/myncbi/susan.pressler.1/bibliography/40451800/public/?sort=date&direction=ascending

D. Research Support
Ongoing Research Support
5R01NR016116   (Pressler/Giordani)   09/15/2016-06/30/2021
NIH/NINR
Cognitive Intervention to Improve Memory in Heart Failure Patients
The purpose of this 3-arm randomized controlled trial is to conduct a test of the computerized cognitive training intervention BrainHQ against a computer-based general cognitive stimulation crossword puzzle intervention (active control) and a usual care control group to improve memory, serum BDNF, and secondary outcomes.
Role: MPI

R01NR016116S   (Pressler/Giordani)   06/01/2019-05/31/2021
NIH/NINR
Cognitive Intervention to Improve Memory in Heart Failure Patients
The purpose of this supplement is to evaluate long-term efficacy of computerized cognitive training intervention BrainHQ against a computer-based general cognitive stimulation crossword puzzle intervention and usual care to lower risk of amnestic mild cognitive impairment and Alzheimer disease/related dementias at 36 months.
Role: MPI

1R01HS025411-01   (Pang)   08/01/2017-08/31/2021
AHRQ
Using Short Stay Units Instead of Routine Admission to Improve Patient Centered Health Outcomes.
The purpose of this multisite randomized clinical trial is to compare effectiveness of short-stay units and traditional hospital units on patient-centered outcomes among patients with acute heart failure.
Role: Co-I

American Heart Association   (Jung)   07/01/2018-06/20/2021
A Virtual Reality Intervention to Improve Attention in Heart Failure Patients
The aims of this career development award are to 1) examine efficacy of the natural restorative environment intervention in virtual reality format on improving attention, self-care, and health-related quality of life among patients with heart failure; and 2) investigate possible biomarkers of attention.

Role: Primary Mentor

R21 NR018281-01A1   (Kitsiou)   08/01/2019-06/30/2021
NIH/NINR
An Innovative Mobile Health Intervention to Improve Self-care in Patients with Heart Failure
The purpose of this study is to conduct a pilot randomized controlled trial to evaluate feasibility and preliminary efficacy of iCardia4HF on self-care, hospitalizations, and quality of life among patients with heart failure.
Role: Co-I

T-32 NR018407   (Rawl/Pressler)   07/01/2019-06/30/2024
NIH/NINR
Advanced Training in Self-Management Interventions for Serious Chronic Conditions
The goal of this training program is to educate pre- and postdoctoral fellows in self-management of serious chronic conditions (e.g., heart failure, cancer, Alzheimer disease) to conduct independent research.
Role: Co-Director

Indiana University School of Nursing   (Hacker)   02/01/2020-01/31/2021
Center for Enhancing Quality of Life in Chronic Illness
Phenotypic Characterization of Persistent Fatigue in Allogeneic Hematopoietic Cell Transplantation Survivors
The goal of this study is to provide comparison data for the aHCT survivor group with persistent fatigue compared to aHCT with occasional tiredness.
Role: Co-I

Indiana University School of Nursing   (Wierenga)   02/01/2020-01/31/2021
Center for Enhancing Quality of Life in Chronic Illness
Emotion regulation intervention to sustain physical activity in rural-dwelling people after myocardial infarction
The goals of this study are to provide refine and pilot test an emotion regulation intervention to improve and sustain adherence to physical activity among rural-dwelling women and men after myocardial infarction.
Role: Co-I

Jonas Center and Sigma Theta Tau   (Wierenga)   07/01/2020-06/30/2021
International Research Award
Emotion regulation intervention to sustain physical activity in rural-dwelling people after myocardial infarction
The goals of this study are to provide refine and pilot test an emotion regulation intervention.
Role: Co-I

Sigma Theta Tau International   (Smith)   12/01/2020-11/30/2021
Alpha Chapter
Phenotyping the pain of heart failure: Characterization, predictors, and outcomes
The overall goal of this study is phenotype the pain experienced by patients with heart failure.
Role: Co-I

Completed Research Support (Selected from last three years)
National Alzheimer's Coordinating Center   (Jung)   07/01/2017 – 12/31/2019
Testing a Model of Cognitive Function with APOE and BDNF Genes and Heart Failure
The purpose of this study is to test a model of cognitive function by examining genetic risk factors and heart failure (HF) in adults with and without cognitive impairment.
Role: Co-I

Midwest Royal Center for Health Promotion and Translation   (Kitsiou)   06/01/2018 – 05/31/2020
iCardia4HF: A Pt-centered Mobile Health Intervention to Promote Self-management and Improve Patient Outcomes in CHF
The goal of this study is to evaluate the feasibility and preliminary efficacy of iCardia4HF on self-care, hospitalizations, and quality of life in patients with heart failure. Role: Co-I

BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors.
Follow this format for each person. **DO NOT EXCEED FIVE PAGES.**

NAME: Carpenter, Janet S., PhD, RN, FAAN

eRA COMMONS USER NAME (credential, e.g., agency login): carpentj

POSITION TITLE: Distinguished Professor and Associate Dean for Research

EDUCATION/TRAINING *(Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.)*

INSTITUTION AND LOCATION	DEGREE *(if applicable)*	Completion Date MM/YYYY	FIELD OF STUDY
Oakland University, Rochester, MI	BSN	05/1988	Nursing, Psychology
University of Kentucky, Lexington, KY	MSN	12/1992	Nursing
University of Kentucky, Lexington, KY	PhD	05/1996	Nursing
University of Kentucky, Lexington, KY	Post-Doc	06/1998	Behavioral Science

A. Personal Statement

I am delighted to serve as co-investigator with Drs. Sanford, Elkins, Nangia, Ellis, and Rand. I bring expertise in two areas to this project. First, I am a clinical and translational scientist with 24 years' experience in research and research training. I have led and managed complex research studies, including those using in home data collection devices for real time data capture. Most of my work is in symptom science, particularly menopausal hot flashes. I have built theoretical models (with Dr. Rand), studied physiological mechanisms and led or helped lead trials testing interventions for menopausal symptoms including clinical hypnosis (with Dr. Elkins), paced respiration, exercise, yoga, medications, and omega-3 fatty acids. My research has been well-funded (> $4 million as PI [including 2 R01s, 1 U01], > $36 million as CoI), well-published, presented nationally and internationally, and highly cited (> 8,800 times). I have also served as co-director, sponsor, or mentor contributing to > $9.2 million in research training grants [including 1 R25, 3 T32s, 2 F31s, 3 KL2s, 1 K01]. I have mentored 20 junior faculty, 8 postdoctoral fellows, and 14 PhD, 8 MSN, and 8 BSN honors students. I regularly review for professional journals. I have served on study sections for the American Cancer Society, California Breast Cancer Research Program, Department of Defense, and National Institutes of Health. I am past chair of the NIH/CSR study section Behavioral Medicine, Interventions and Outcomes.
Second, I have been involved in studies related to medication management (with Dr. Ellis) and aromatase inhibitor adherence. Because menopausal hot flashes are a major side effect of aromatase inhibitors for breast cancer treatment, I have been involved in three medication adherence projects: as a co-investigator on a NIH/NIGMS U01 funded study comparing exemestane to letrozole and evaluating medication switching and non-persistence; on an AHRQ funded R36 dissertation study evaluating decision making related to aromatase inhibitor initiation, switching, and non-persistence; and on an unfunded dissertation generating an ontology to represent aromatase inhibitor adherence-related knowledge. I am so pleased to have developed this new collaboration with Dr. Sanford to move this second line of research forward.

B. Positions and Honors
Positions and Employment
1994-1996   Predoctoral Trainee in Psychosocial Breast Cancer Research, Department of Behavioral Science, College of Medicine, University of Kentucky, Lexington, KY
1996-1998   NIMH Postdoctoral Research Fellow, Department of Behavioral Science, College of Medicine, University of Kentucky, Lexington, KY

1998-2002	Assistant Professor, School of Nursing, Vanderbilt University, Nashville, TN
1998-2003	Member, Vanderbilt-Ingram Cancer Center, Vanderbilt University, Nashville, TN
2000-2002	Research Deputy Director, Vanderbilt-Ingram Cancer Center Pain and Symptom Management Team, Nashville, TN
2002-2003	Associate Professor, School of Nursing, Vanderbilt University, Nashville, TN
2003-2008	Associate Professor, Indiana University (IU) School of Nursing, Indianapolis, IN
2003-now	Member, IU Melvin and Bren Simon Cancer Center, Indianapolis, IN
2008-2014	Professor, Indiana University School of Nursing, Indianapolis, IN
2011-2015	Sally Reahard Chair and Director, Center for Enhancing Quality of Life in Chronic Illness, IU School of Nursing, Indianapolis, IN
2011-2016	Member, Indiana Institute for Personalized Medicine, IU School of Medicine, Indianapolis, IN
2013-2017	Co-director, T32 Training in Behavioral Nursing Research, IU School of Nursing, Indianapolis, IN
2014-now	Affiliated Investigator, Regenstrief Institute, Inc., Indianapolis, IN
2014-now	Associate Dean for Research, IU School of Nursing, Indianapolis, IN
2015-now	Distinguished Professor, IU statewide, all campuses
2020-now	Audrey Geisel Endowed Chair in Innovation, IU School of Nursing, Indianapolis, IN

Other Experience

2002-2006	Reviewer, ACS Doctoral and Masters Scholarships in Cancer Nursing
2001-2002	Reviewer, USAMRMC Behavioral and Social Sciences Breast Cancer Panel
2003	Reviewer, NIH Long Term Cancer Survivors Scientific Review Group
2003-2005	Member, ONS Major Grants Review Team
2004	Invited Faculty, NCCAM/NIH Workshop on Hot Flash Management
2004	Faculty, ONS State of the Science Workshop on Sleep Disturbance and Cancer
2005	Invited Presenter, NIH State of the Science: Management of Menopause Related Symptoms
2006-2007	Chair, ONS Major Grants Review Team
2006	Reviewer, NIH Special Emphasis Panel Health of the Population ZRG1 HOP-S 03 M
2007-2008	Reviewer, ACS Pilot and Exploratory Projects (PEP2)
2008-2011	Reviewer, NIH Behavioral Medicine Interventions and Outcomes Study Section
2011-2013	Chair, NIH Behavioral Medicine Interventions and Outcomes Study Section
2014	Reviewer, NIH Mechanisms of Emotion, Stress, and Health ZRG1 BBBP-V
2015	Reviewer, NIH Integrative Clinical Endocrinology and Reproduction (ICER) Study Section
2017	Reviewer, NIH Stimulating Innovations in Intervention Research for Cancer Prevention and Control ZRG1 RPHB E
2018	Reviewer, Risk, Prevention and Health Behavior (RPHB) Integrated Review Group, Division of AIDS, Behavior and Population Sciences (DABP) and ZRG1 RPHB-W (02), Psychosocial Risks and Disease Prevention
2019-now	Editorial Board, *Menopause: The Official Journal of the North American Menopause Society*
2020-now	Editorial Board, *Women's Midlife Health*
2020-now	Editorial Board, *Nursing Outlook: The Official Journal of the American Academy of Nursing*
2020-now	Board of Directors, North American Menopause Society

Professional Memberships

1987-now	Sigma Theta Tau International Society of Nursing
1988-now	Florence Nightingale Society, Honorary Lifetime Member
1990-2020	Oncology Nursing Society
1996-2019	Society for Behavioral Medicine
1998-now	North American Menopause Society
2003-now	Midwest Nursing Research Society
2006-now	International Menopause Society
2007-now	American Nurses' Association/Indiana State Nurses' Association
2007-now	Council for the Advancement of Nursing Science
2009-now	American Academy of Nursing

Honors (selected)

1999	Oncology Nursing Society New Investigator Award
2003	Oncology Nursing Society S Baird Oncology Excellence in Writing Nursing Research Award
2005	Oncology Nursing Society/American Cancer Society State of the Science Lectureship
2007	North American Menopause Soc./Duramed Pharmaceuticals Vasomotor Symptoms Research Award
2008	Midwest Nursing Research Society Senior Scientist Award
2009	Fellow, American Academy of Nursing
2010	Outstanding Alumnus, University of Kentucky College of Nursing
2012	Excellence in Mentoring, Sigma Theta Tau International Honor Society, Alpha Chapter
2013	Distinguished Contributions Award, Midwest Nursing Research Society
2013	Honored Researcher, Midwest Nursing Research Society
2014	Outstanding Nurse Scientist, Council for the Advancement of Nursing Science
2016	Outstanding Women Faculty Leader, Indiana University-Purdue University, Indianapolis, IN
2016	International Nurse Researcher Hall of Fame, Sigma Theta Tau International Honor Society of Nursing
2017	Indiana Woman of Achievement
2020	USA Today Most Influential Women of the Century (Indiana)
2021	Indiana University Bicentenial Medal

C. Contribution to Science

1. As Co-investigator, sponsor and mentor, I have helped document the problem of non-adherence to aromatase inhibitors. As Co-investigator on a multi-site U01 trial (Flockhart PI), our team showed that medication switching and non-persistence were ubiquitous issues with aromatase inhibitors. This work led to additional work with 2 PhD students. As sponsor on an AHRQ funded R36 dissertation study, our team showed that decision making related to medication non-adherence was a process that unfolded over time and encompassed 4 stages: being told what I need to do to live, doing what I need to do to live, enduring what I need to do to live, and deciding how I want to live. We also identified 6 sources of decisional supports that met 5 different types of decisional needs. As mentor to another doctoral student, our team published literature reviews and developed an ontology related to knowledge about aromatase inhibitor adherence. This work has led to my role on a multi-disciplinary, multi-site team to test a theoretical model related to aromatase inhibitor adherence (Ellis is also CoI on this project).

   a. Rivers AS, Sanford K, Elkins G, **Carpenter** JS, Rand KL, Bartlett Ellis RJ. Attitudinal and social predictors of adherence to oral endocrine therapy: A psychometrically-informed model. J Health Psychol. 2020 Dec 18:1359105320982039. doi: 10.1177/1359105320982039. Epub ahead of print. PMID: 33339482.

   b. Milata, J. L, Otte, J. L **Carpenter**, J. S. (2018) Oral endocrine therapy nonadherence, adverse effects, decisional support, and decisional needs in women with breast cancer. Cancer Nursing, 41(1), E9-E18. PMCID: PMC5316408.

   c. Kadakia, K., Snyder, C., Kidwell, K., Seewald, N., Storniolo, A., Flockhart, D., Skaar, T., Desta, Z., Rae, J., **Carpenter**, J.S., Otte, J., Hayes, D., Stearns, V., & Henry, N. (2016). Patient-reported outcomes and early discontinuation in aromatase inhibitor-treated postmenopausal women with early stage breast cancer. *The Oncologist*, 21(5), 539-546. PMCID: PMC4861358.

   d. Kidwell, K. M., Harte, S. E., Hayes, D. F. Storniolo, A. M., **Carpenter**, J. S., Flockhart, D. F., Stearns, V., Clauw, D. J., Williams, D. A., Henry, N. L. (2014). Patient-reported symptoms and discontinuation of adjuvant aromatase inhibitor therapy. *Cancer*, 120(16), 2403-2411. PMCID: PMC4126845.

2. Well-designed, randomized controlled trials are needed for evidence-informed management of menopausal hot flashes in clinical practice. I have conducted clinical trials testing various therapies as PI on 3 large NIH grants (2 R01s, 1 U01) and CoI on 2 NIH grants (U01, U34). I was invited as the only nurse to lead a clinical site within the MsFLASH national research network. This network was funded by the National Institutes of Health for > $20 million to conduct clinical trials to generate evidence to manage menopausal hot flashes and other symptoms. MsFLASH and other research I have led or co-led has generated new evidence for various hot flash treatments: behavioral therapies (slow breathing, yoga, exercise, clinical hypnosis), dietary supplements (fish oil), and medications (venlafaxine, low dose estrogen, escitalopram). In 2015, I served as invited Chair for the North American Menopause Society's statement on non-hormonal management of menopausal symptoms, thereby speeding translation of this research into policy.

a. **Carpenter, J.S.,** Storniolo, A.M., Johns, S., Monahan, P.O., Azzouz, F., Elam, J.L., Johnson, C.S., & Shelton, R.C. (2007). Randomized double-blind, placebo-controlled crossover trials of venlafaxine for hot flashes after breast cancer. *Oncologist, 12*(1):124-35: PMID: 17227907

b. Guthrie KA, LaCroix AZ, Ensrud KE, Joffe H, Newton KM, Reed SD, Caan B, **Carpenter** JS, Cohen LS, Freeman EW, Larson JC, Manson JE, Rexrode K, Skaar TC, Sternfeld B, Anderson GL. (2015). Pooled analysis of 6 pharmacologic and behavioral interventions for menopausal vasomotor symptoms. *Obstetrics & Gynecology*, 126(2), 413-422. PMCID: PMC4526122.

c. **Carpenter, J.S.,** Burns, D.S., Wu, J., Otte, J., Schneider, B., Ryker, K., Tallman, E., Yu, M. (2013). Paced respiration for vasomotor and other menopausal symptoms: A randomized controlled trial. *J Gen Intern Med, 28*(2):193-200. PMCID: PMC3614127

d. **Carpenter, JS,** Gass MLS, Maki PM, Newton KM, Pinkerton JV, Taylor M, Utian WH, Pike C. (2015). Nonhormonal management of menopause-associated vasomotor symptoms: 2015 position statement of the North American Menopause Society. *Menopause, 22*(11):1152-72

3. I developed new questionnaires and new physiological measures to assess not flashes in real time at home, as well as evaluated the reliability and validity of existing tools. In the late 1990's, I developed and tested The Hot Flash Related Daily Interference Scale. During the same time period, I began work as the first nurse to develop, test, and refine physiological monitoring systems to measure hot flashes in real time at home. I am known internationally for this work and have trained individuals in 7 countries to use these systems (USA, Canada, Australia, Switzerland, Denmark, France, UK). In partnership with 2 different manufacturing companies, I directed efforts to decrease the size and vastly improve these measurement systems (e.g., greater data storage capability, more refined analytic software, and simplified data output). I was a pioneer in documenting how such measures can be used to better understand women's experiences of hot flashes and how different hot flash treatments affect women. My leadership in this area is recognized by: (1) the frequent citations of publications related to physiological measures; (2) invited presentations at venues hosted by the NIH; and (3) acting on teams to lead the nation in using hot flash measurement guidelines in 2005 and 2012.

a. **Carpenter** JS, Bakoyannis G, Otte JL, Chen CX, Rand KL, Woods NF, Newton KM, Joffe H, Manson JE, Freeman EW, Guthrie KA. (2017). Validity, cutpoints, and minimally important differences for two hot flash related daily interference scales. *Menopause*, 24(8), 877-885. PMCID: PMC6002749.

b. **Carpenter, J.S.,** Newton, K.N., Sternfeld, B.S., Joffe, H., Reed, S.R., Ensrud, K.E., & Milata, J. (2012). Laboratory and ambulatory evaluation of vasomotor symptom monitors from the Menopause Strategies Finding Lasting Answers for Symptoms and Health network. *Menopause, 19*(6):664-71. PMCID: PMC3326209

c. Otte, J. L., Flockhart, D., Hayes, D., Henry, L., Schneider, B., Stearns, V., Storniolo, A. M., Azzouz, F., Hayden, J., Lemler, S., Nguyen, A., Jeter, S., & Shaverdi, K., & **Carpenter,** J. S. (2009). *C*omparison of subjective and objective hot flash measures over time among breast cancer survivors initiating aromatase inhibitor therapy. *Menopause,*16(4), 653-659. PCMID: PMC2817995

d. **Carpenter, J.S.,** & Andrykowski, M.A. (1998). Psychometric evaluation of the Pittsburgh sleep quality index. *J Psychosom Res, 45*:5-13. PMID: 9720850

Complete List of Published Work in MyBibliography:
https://www.ncbi.nlm.nih.gov/myncbi/janet.carpenter.1/bibliography/public/

D. Research Support
Ongoing Research Support
No Number, University Research Support Funds Grant Zhang (PI)   12/1/2020-11/30/2021
Machine learning-enabled vasomotor symptom monitor
To test an ambulatory vasomotor symptom tracker and design and develop machine learning analysis software.
Role: Co-investigator

No number, Indiana CTSI   Carpenter / Tisdale (MPI)   05/01/2020-08/31/2021
Phenotypic characterization of menopausal palpitations
To establish a new collaboration with the purpose of characterizing palpitations in menopausal women using existing data from two NIH-funded studies.
Role: Multi PI

T32CA117865   Champion (PI)   09/01/16-08/31/21
Interdisciplinary Training in Behavioral Oncology
To train pre-doctoral students and post-doctoral fellows in multi-disciplinary behavioral oncology research to help develop a new generation of researchers who can integrate basic, clinical, and behavioral sciences.
Role: Mentor to postdoctoral fellow

Completed Research Support (past 3 years)
Pfizer 36068923   Carpenter (PI)   11/01/17 – 05/31/19
Impact of the "Hot Flashes? Cool!" Prototype Exhibit on Learning and Change Outcomes
To evaluate an initial prototype version of an art exhibit designed to educate the public about menopausal hot flashes.
Role: PI

IU Extraordinary Opportunities Grant   Carpenter (PI)   05/01/18-06/30/19
Creative Arts for Science Education: The 'Hot Flashes? Cool!' Exhibit
To plan, fundraise, and build portions of a full-scale exhibit that uses the creative arts to educate the public about the scientific facts about menopausal vasomotor symptoms.
Role: PI

1U01HG007762-01   Skaar/Dexter (MPI)   09/01/14-08/31/18
Embedding Pharmacogenotyping in an Integrated Health System for the Underserved
To pilot a genomic platform in a large safety-net health care system and measure the economic costs and clinical outcomes of doing so.
Role: Co-Investigator

8ULTR001108   Shekhar (PI)   07/01/14-04/30/18
Indiana Clinical and Translational Sciences Institute (I-CTSI)
The mission of the I-CTSI is to be integrated home for clinical and translational research that creates a shared, investigator-friendly institutional environment and provides easily accessible resources and services to conduct the highest-quality research dedicated to improving human health across Indiana and beyond.
Role: Co-Investigator

BIOGRAPHICAL SKETCH
Provide the following information for the Senior/key personnel and other significant contributors.
Follow this format for each person. **DO NOT EXCEED FIVE PAGES.**

NAME: Robin P. Newhouse

eRA COMMONS USER NAME (credential, e.g., agency login): rnewhou1

POSITION TITLE: Dean, Distinguished Professor, and Deputy Chair

EDUCATION/TRAINING *(Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.)*

INSTITUTION AND LOCATION	DEGREE *(if applicable)*	Completion Date MM/YYYY	FIELD OF STUDY
Anne Arundel Community College, Arnold, MD	AA	05/1976	Nursing
University of Maryland Baltimore County, Baltimore, MD	BS	05/1987	Nursing
University of Maryland University College, College Park, MD	MGA	05/1991	Health Care Administration
University of Maryland Baltimore, School of Nursing, Baltimore, MD	MS	05/1999	Nursing
University of Maryland Baltimore, School of Nursing, Baltimore, MD	PhD	08/2000	Nursing

A. Personal Statement

My program of research focuses on comparative effectiveness of health system interventions and implementation science to foster adoption of evidence-based care processes to improve care and patient outcomes. My research demonstrates a record of productive multi-site pragmatic, with inclusion of PhD students and mentees in all aspects of the study.

B. Positions and Honors

Positions & Employment
2002-2005	Adjunct Faculty, Assistant Professor, School of Nursing, University of Maryland, Baltimore, MD
2002-2007	Assistant Professor, Johns Hopkins University School of Nursing, Baltimore, MD
2004-2007	Co-Chair of Institutional Review Board Expedited Review Committee, The Johns Hopkins Medicine Institutional Review Board, Baltimore, MD
2007-2008	Adjunct Faculty, Johns Hopkins University School of Nursing, Baltimore, MD
2008	Lecturer, Health Sciences of Loyola University, Chicago, IL
2010	Visiting Professor, College of Nursing, Kaohsiung Medical University, Kaohsiung, Taiwan
2007-2011	Assistant Dean for the Doctor of Nursing Practice (DNP) Program, Associate Professor (with tenure), University of Maryland School of Nursing, Baltimore, MD
2010-2011	Co-Director of the Developing Center of Healthcare System Outcomes, University of Maryland School of Nursing, Baltimore, MD
2011-2012	Chair and Associate Professor (with tenure), Organizational Systems and Adult Health, University of Maryland School of Nursing, Baltimore, MD
2011-2017	Research Investigator (WOC), Veterans Affairs Maryland Health Care System, Baltimore, MD
2012-2015	Chair and Professor (with tenure), Organizational Systems and Adult Health, University of Maryland School of Nursing, Baltimore, MD

	Co-Director of the Center for Health Outcomes Research Organized Research Center at the University of Maryland Baltimore, Baltimore, MD
2015-2017	Professor, Indiana University School of Nursing, Indianapolis, IN
2015-present	Dean, Indiana University School of Nursing, Indianapolis, IN
2015-present	Deputy Chair, University Clinical Affairs Cabinet, Indiana University, Indianapolis, IN
2015-present	Associate Vice President for Academic Affairs, IU Health, Indianapolis, IN
2017-present	Distinguished Professor, Indiana University

Other Experience & Professional Memberships

2008–2017	Member and Chair (2014-2016), Research Council, American Nurses Credentialing Center
2011-present	Member, Methodology Committee of the Patient-Centered Outcomes Research Institute (PCORI)
2012-2013	Vice Chair, Methodology Committee of PCORI
2013-2019	Chair, Methodology Committee of PCORI
20192-present	Vice Chair, Methodology Committee of PCORI
2012-2014	Member, Institute of Medicine Standing Committee on Credentialing Research in Nursing
2012-2015	Member, AcademyHealth Alice S. Hersh New Investigator Award Selection Committee
2014	Member, Institute of Medicine Planning Committee, Future Directions of Credentialing Research in Nursing: A Workshop
2014-2015	Member, Institute of Medicine Consensus Committee, Treatment of Cardiac Arrest: Current Status and Future Directions
2014-2015	Co-Chair, American Academy of Nursing (AAN) and American Nurses Association (ANA) Care Coordination Task Force
2014-2016	Associate Editor, Worldviews on Evidence-Based Nursing
2014-2020	Elected Member, Board of Directors AcademyHealth (Board Chair 2018, Past Chair 2019-2020)
2014-2018	National Advisor for the Clinical and Nursing Advisory Board National Center for Patient and Family Engagement for GetWellNetwork
2015-present	Member, Midwest Nursing Research Society
2017-present	Elected Member, National Academy of Medicine (NAM)
2019	Member, National Academies of Sciences, Engineering, and Medicine Committee on Examination of Integration of Opioid and Infectious Disease Prevention Efforts in Select Programs

Honors

2011	Inducted as Fellow, American Academy of Nursing
2013	Women's Health Issues, Honorable Mention for Gibbs Prize (Johantgen et al., 2012)
2012	Nursing Economic$/Margaret Sovie Writer's Award (Newhouse et. 2011)
2013-2014	University of Maryland Baltimore Champion of Excellence
2013-2016	National Research Mentor for Robert Wood Johnson Foundation Nurse Faculty Scholar
2014	Nurse Researcher Hall of Fame, Sigma Theta Tau International Honor Society of Nursing
2014	Researcher of Year, University of Maryland, Baltimore Founder's Week Award
2015	American Nurses Credentialing Center President's Award
2017	The Dorothy Garrigus Adams Award for Excellence in Fostering Professional Standards, Sigma Theta Tau International Honor Society of Nursing Founders Award
2018	University of Maryland Baltimore School of Nursing Distinguished Alumni
2019	University of Maryland Baltimore School of Nursing Visionary Pioneer
2019	Distinguished Evidence-based Practice Trailblazer Award

C. Contributions to Science

Contributions to science include pragmatic studies to test health systems interventions to improve the quality of care across settings (academic medical centers as well as rural and community hospitals), developing evidence translation models now use globally, and leadership in development of methodological standards for comparative effectiveness research.

1. Health Services Research. Multi-site research is conducted in rural, community and academic settings with clinician partners testing interventions to improve care quality and patient outcomes. Partners with clinicians to tailor interventions to research naïve settings.

   a. Harris, A.D., Pineles, L., Belton, B., Johnson, J.K., Shardell, M., Loeb, M., **Newhouse, R.**, et al. (2013). Universal Glove and Gown use and Acquisition of Antibiotic-Resistant Bacteria in the ICU: A Randomized Trial. *JAMA*, *310*(15), 1571-1580. PMCID: PMC4026208

   b. **Newhouse, R.P.,** Byon, H.D., Storkman, E., Johantgen, M.   (2018). Multi-Site Studies Demonstrate Positive Relationship between Practice Environments and Smoking Cessation Counseling Evidence-based Practices. *Worldviews on Evidence-based Nursing*, 15: 3, 217-224. http://onlinelibrary.wiley.com/doi/10.1111/wvn.12277/epdf. PMID: 29528194

   c. **Newhouse, R. P.,** Janney, M., Gilbert, A., Agley, J., Bakoyannis, G., Ferren, M., Mullins, C. Daniel, Johantgen, M., Schwindt, R., Thoele, K. (2018). Study Protocol Testing Toolkit versus Usual Care for Implementation of Screening, Brief Intervention, Referral to Treatment in Hospitals: A Phased Cluster Randomized Approach. *Addiction Science & Clinical Practice*, 13:28. Available at: https://doi.org/10.1186/s13722-018-0130-4. PMID: 30587235. PMCID: PMC6307302

   d. Vaughn, S.X., Maxey, H.L., Keen, A., Thoele, K., **Newhouse, R.** Assessing public behavioral health services data: a mixed method analysis. Substance Abuse Treatment and Prevention Policy. (2020). Nov 11;15(1):85. doi: 10.1186/s13011-020-00328-9   PMID: 33176839; PMCID: PMC7661157.

2. Evidence translation models. Have had national and global impact in evidence translation through development and adoption of two models used to translate evidence to practice [Evidence-based Behavioral Practice Model was Milbank Quarterly top downloads in 2009 and training available online (sponsored by NIH, OBSSR and others); The Johns Hopkins Nursing Evidence-based Practice model received the International Award for Research Utilization by the Honor Society for Nursing (2005) and is now used internationally to guide nurse and health system clinical decisions].

   a. **Newhouse, R.P**., Dearholt, S., Poe, S., Pugh, L.C., White, K. (2007). Organizational Change Strategies for Evidence-based Practice. *Journal of Nursing Administration, 37*(12), 552-557.

   b. Satterfield, J., Spring, B., Brownson, R.C., Mullen, E., **Newhouse, R**., Walker, B. Whitlock, E. (2009). Toward a Transdisciplinary Model of Evidence-Based Practice, *Milbank Quarterly*, *87*(2), 368-390. PMCID: PMC2698591

3. Methodological Standards. As Chair of the Methodology Committee of the Patient Centered Outcomes Research Institute (PCORI) Newhouse works to advance minimum standards for comparative effectiveness research. Has been advanced. The first set of standards in 2012 to guide the conduct of studies funded by PCORI with revisions and development of new standards ongoing.

   a. **Newhouse, R.P**., Bobay, K, Dykes, P.C., Stevens, K.R., Titler, M. (2013). Methodology Issues in Implementation Science*. Medical Care*, *51*, S32-S40. PMID: 23502915

   b. Fleurence, R., Whicher, D, Dunham, K., Gerson, J., **Newhouse, R.,** Luce, B. (2015). The Patient-Centered Outcomes Research Institute's Role in Advancing Methods for Patient-Centered Outcomes Research. *Medical Care*, *53*(1), 2-8. PMCID: PMC4336314

   c. **Newhouse, R.P.,** Barksdale, D., Miller, J. Research Done Differently: The Patient-Centered Outcomes Research Institute (PCORI). (2015). *Nursing Research*, *64*(1), 72-77. PMID: 2552063

   d. Patient-Centered Outcomes Research Institute (PCORI) Methodology Committee. (2019). The PCORI Methodology Report. Available at: http://www.pcori.org/sites/default/files/PCORI-Methodology-Report.pdf

Complete List of Published Work in MyBibliography:
http://www.ncbi.nlm.nih.gov/pubmed/?term=robin+newhouse

D. Additional Information: Research Support and/or Scholastic Performance

Ongoing Research Support
VFGC-020   Newhouse, R.P. (PI)   11/01/2017-10/31/2022
IU Health
***Screening, Brief Intervention, Referral to Treatment (SBIRT) Dissemination: A Phased Cluster
Approach Across Five Regions in IU Health System.***

Indiana University Health Values Fund Grand Challenge Grant No. VFGC-020 and the Indiana Clinical and
Translational Sciences Institute funded, in part by Grant #*UL1TR002529* from the National Institutes of Health,
National Center for Advancing Translational Sciences, Clinical and Translational Sciences Award, September
1, 2020-August 31, 2022.
Role: Principal Investigator

Indiana University (IU)   Newhouse, R.P. (PI)   11/01/2017-10/31/2022
IU Grand Challenge: Responding to the Addictions Crisis

This $50 million dollar five year Grand Challenge will focus on responding to the addictions crisis in Indiana in
partnership with Governor Holcomb, our major health care providers (IU Health and Eskenazi Health), and a
growing number of communities and agencies on the front lines. The approach is a coordinated,
comprehensive, multifaceted and integrated strategy focusing on: 1) Reducing the incidence of Substance Use
Disorders (SUD), 2) Decreasing opioid deaths, and 3) Decreasing the number of babies born with Neonatal
Abstinence Syndrome. IU's five areas of focus are: 1) data sciences and analysis, 2) education, training and
certification, 3) policy analysis, economics and law, 4) basic, applied and translational research, and 5)
community and workforce development.
Role: Lead Investigator

VFGC-020   Newhouse, R.P. (PI)   08/01/2017-12/31/2021
IU Health
***Phased Multisite Cluster Randomized Trial Testing Screening, Brief Intervention, Referral to Treatment
for People that Use Tobacco, Alcohol, and Non-prescription Drugs***

The proposed phased cluster randomized trial of hospitals will inform SBIRT implementation methods for use
across rural, community and urban settings across 14 acute care facilities throughout the IU Health system
through a mixed methods approach. The long-term objective is to develop an SBIRT toolkit to disseminate and
sustain SBIRT use to increase the screening of substance use, the delivery of brief interventions, and referral
to treatment services.
Role: Principal Investigator

Completed Research Support (within one year)

Indiana University (IU)   Newhouse, R.P. (PI)   1/01/2018-12/31/2019

Workforce and Capacity Assessment for People Referred to Treatment Post Hospital Discharge
This project creates sustainable referral to treatment processes across IU Health for people with risky alcohol
and drug use. The approach includes geographic mapping of the addictions workforce in IU Health market zip
codes, organizational survey to assess the workforce in approved treatment locations, recommendations to IU
Health improve the distribution and characteristics of the addictions workforce to address patient needs and
the development of a web-based resource for referral to treatment. The long-term goal is to reduce substance
use disorders by increasing the number of persons in recovery.
Role: Principal Investigator

BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors.
Follow this format for each person. **DO NOT EXCEED FIVE PAGES.**

NAME: Perkins, Susan Marie (Minick)

eRA COMMONS USER NAME (credential, e.g., agency login): SPERKIN1

POSITION TITLE: Professor

EDUCATION/TRAINING *(Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.)*

INSTITUTION AND LOCATION	DEGREE *(if applicable)*	Completion Date MM/YYYY	FIELD OF STUDY
Eastern Michigan University	B.S.	12/1986	Mathematics
Eastern Michigan University	M.A.	05/1989	Mathematics
University of Michigan	M.S.	05/1992	Biostatistics
University of Michigan	Ph.D.	05/1997	Biostatistics

A. Personal Statement

I am a Professor of Biostatistics and the Director of the Biostatistics, Epidemiology, and Research Design Program of the Indiana Clinical Translational Science Institute (PI: A. Shekhar, UL1TR001108) and was also the Biostatistics and Data Management Core Director for the IU Melvin and Bren Simon Cancer Center from 2006-2017 (PI: P. Loehrer, P30 CA082709-16). Most importantly, I was the Biostatistics Core Director for the Center for Enhancing Quality of Life in Chronic Illness (CEQL) from 2002 to 2014, and currently provide guidance to IU School of Nursing (SON) faculty (including CEQL awardees) through the IU SON Office of Research Support. In addition, I have been a co-investigator on many NIH funded grants with IU SON faculty where I contributed to both securing the funding and analyzing and disseminating the results. A few representative publications with CEQL-funded investigators are listed below. I have extensive statistical experience, serving as biostatistician or Co-Investigator on 33 funded studies and am primary author or co-author on 174 peer-reviewed publications (63 of which emanated from IU SON faculty research). Thus, I am very well-suited to provide statistical expertise for CEQL.

1. Holochwost S, Robb S, Henley AK, Stegenga K, **Perkins SM**, Russ KA, Jacob SA, Delgado D, Haase JE, Krater CM. Active Music Engagement and Cortisol as an Acute Stress Biomarker in Young Hematopoietic Stem Cell Transplant Patients and Caregivers: Results of a Single Case Design Pilot Study. Frontiers in Psychology 2020 Nov 2;11:587871. doi: 10.3389/fpsyg.2020.587871.
2. Russ KA, Holochwost SJ, **Perkins SM**, Stegenga K, Jacob SA, Delgado D, Henley AK, Haase JE, Robb SL. Cortisol as Acute Stress Biomarker in Young Hematopoietic Cell Transplant Patients/Caregiver: Active Music Engagement Protocol. Journal of Alternative and Complementary Medicine 2020 May;26(5):424-434. doi: 10.1089/acm.2019.0413. PMCID: PMC7232696.
3. Robb SL, Haase JE, **Perkins SM**, Haut PR, Henley AK, Knafl KA, Tong Y. Pilot Randomized Trial of Active Music Engagement Intervention Parent Delivery for Young Children With Cancer. Journal of Pediatric Psychology 2017 Mar; 42 (2): 208-219. doi: 10.1093/jpepsy/jsw050.
4. Welch JL, Ellis RJB, **Perkins SM**, Johnson CS, Zimmerman LM, Russell CL, Richards C, Guise DM, Decker BS. Knowledge and Awareness among Patients with Stage 3 Chronic Kidney Disease. Nephrology Nursing Journal 2016 Nov/Dec; 43(6), 513-5.

B. Positions and Honors

C. Contributions to Science

I have been focusing in the area of cancer research since 2006, when I became the Director of the Biostatistics Core for the Indiana University Melvin and Bren Simon Cancer Center. I contribute to the design, statistical analyses, and dissemination of results of cancer-related studies in both pre-clinical and clinical settings. This work has led to better understanding of cancer screening, clinical prediction rules, and better understanding of mechanisms among other areas of research. Representative publications include:

1. Einhorn LH; Williams SD; Chamness A; Brames MJ; **Perkins SM**; Abonour R. High-dose chemotherapy and stem-cell rescue for metastatic germ-cell tumors. New England Journal of Medicine. 2007;357(4):340-348. PMID: 17652649.
2. Hahn NM, Stadler WM, Zon RT, Waterhouse D, Picus J, Nattam S, Johnson CS, **Perkins SM**, Waddell MJ, Sweeney CJ. Phase II Trial of Cisplatin, Gemcitabine, and Bevacizumab As First-Line Therapy for Metastatic Urothelial Carcinoma: Hoosier Oncology Group GU 04-75. J Clin Oncol. 2011 Apr 20;29(12):1525-1530. Epub 2011 Mar 21. PMID: 21422406.
3. Hocevar BA, Kamendulis LM, Pu X, **Perkins SM**, Wang Z, Johnston EL, DeWitt JM, Li L, Loehrer PJ, Klaunig JE, Chiorean EG. Contribution of environment and genetics to pancreatic cancer susceptibility. PLOS ONE 2014 Mar 20;9(3):e90052. doi: 10.1371/journal.pone.0090052. eCollection 2014. PMCID: PMC3961224.
4. **Perkins SM**, Bales C, Vladislav T, Althouse S, Miller KD, Sandusky G, Badve S, Nakshatri H. TFAP2C Expression in Breast Cancer - Correlation with Overall Survival Beyond 10 Years of Initial Diagnosis. Breast Cancer Research and Treatment 2015 Aug;152(3):519-31. doi: 10.1007/s10549-015-3492-2. PMID: 26160249.

I have studied the impact of epilepsy on children with respect to neuropsychological, behavioral and mental health outcomes since 2002. This includes both new onset epilepsy and chronic epilepsy. My contribution has

been to the design, statistical analyses, and dissemination of results of these studies. This work has led to a greater understanding of the impact of epilepsy on children and provided clues for intervention, including:

1. Fastenau PS; Johnson CS; **Perkins SM**; Byars AW; DeGrauw TJ; Austin JK; Dunn DW. Neuropsychological status at seizure onset in children: Risk factors for early cognitive deficits**.** Neurology. 2009;73(7):526-534. PMCID: PMC2730794.
2. Dunn DW; Austin JK; **Perkins SM**. Prevalence of psychopathology in childhood epilepsy: Categorical and dimensional measures**.** Developmental Medicine and Child Neurology. 2009;51(5):364-372. PMCID: PMC2860735.
3. Austin JK; **Perkins SM**; Johnson CS; Fastenau PS; Byars AW; deGrauw TJ; Dunn DW. Self-esteem and symptoms of depression in children with seizures: Relationships with neuropsychological functioning and family variables over time**.** Epilepsia. 2010;51(10):2074-2083. PMID: 20412284.
4. Austin JK; **Perkins SM**; Johnson CS; Fastenau PS; Byars AW; deGrauw TJ; Dunn DW. Behavior problems in children at time of first recognized seizure and changes over the following 3 years**.** Epilepsy and Behavior. 2011;21(4):373-381. PMCID: PMC3182400.

Using technology that takes advantage of the electronic medical record to improve health care is a very important area of research that is continuing to grow. I have spent many years investigating computerized systems to share and utilize electronic medical record data, including interventions to improve patient care using decision support reminders. This has led to improvements in preventative care in the inpatient setting, for example. My contribution has been to the design, statistical analyses, and dissemination of results of these studies. Representative publications include:

1. Dexter PR; **Perkins S**; Overhage JM; Maharry K; Kohler RB; McDonald CJ. A computerized reminder system to increase the use of preventive care for hospitalized patients**.** New England Journal of Medicine. 2001;345(13):965-970. PMID: 11575289.
2. Overhage M; Dexter PR; **Perkins SM**; Cordell WH; McGoff J; McGrath R; McDonald CJ. A randomized, controlled trial of clinical information shared from another institution. Annals of Emergency Medicine. 2002;39(1):14-23. PMID: 11782726.
3. Dexter PR; **Perkins SM**; Maharry KS; Jones K; McDonald CJ. Inpatient computer-based standing orders vs physician reminders to increase influenza and pneumococcal vaccination rates: A randomized trial**.** Journal of the American Medical Association. 2004;292(19):2366-2371. PMID: PMID: 15547164.
4. Dixon BE; Simonaitis L; **Perkins SM**; Wright A; Middleton B. Measuring agreement between decision support reminders: The cloud vs. the local expert**.** BMC Medical Informatics and Decision Making. 2014;14(1). PMCID: PMC4004460.

D. Additional Information: Research Support and/or Scholastic Performance

Ongoing Research Support

1R01NR019190 (Robb)   09/19/19 – 06/30/24
NIH-NINR
Biological Mechanisms and Dosing of Active Music Engagement to Manager Acute Treatment Distress and Improve Health Outcomes in Young Children with Acute Lymphoblastic Leukemia and Parents

This study examines AME's effects on several biomarkers to provide a more holistic understanding about how active music interventions work to mitigate cancer-related stress and its potential to improve immune function. Role: Co-Investigator

1R01CA235632-01 (Haase)   08/13/19 – 07/31/24
Indiana University (cost-share) [NIH]
Evaluation of the Communication Plan Early through End-of-Life (COMPLETE) Intervention

The overall objective of this application is to evaluate the efficacy of COMPLETE (Communication Plan: Early through End of Life), a series of tailored discussions delivered by the child's primary MD/RN dyad, that begin at diagnosis, and integrates visual aids, to empathically facilitate conversations with parents about prognosis,

hopes, and goals-of-care across the cancer continuum. The central hypothesis is that COMPLETE will foster alignment of goals of care between providers and parents when cure is unrealistic, leading to earlier hospice enrollment, reduced use of high-intensity medical interventions, and less pain and emotional suffering in children at EOL and less distress in parents.
Role: Biostatistician

1R21MD015150 (Oruche)   04/01/20 – 03/31/22
NIH-NIMHD
Modification and Evaluation of the DECIDE Intervention to Improve Parent-Provide Interactions in Low-Income Parents of Adolescents with Disruptive Impulse Control, and Conduct Disorders

We propose to modify the evidence-based DECIDE intervention to target low income and/or minority parents and providers of adolescents with DIC. DECIDE stands for Decide the problem; Explore the questions; Closed or open-ended questions; Identify the who, why, or how of the problem; Direct questions to your health care professional; Enjoy a shared solution. DECIDE was developed for ethnically/racially diverse adult patients with serious mental illness and the latest evidence-based iterations include intervention components targeted to and shown to increase patient activation, provider communication, and patient-provider interactions.
Role: Co-I

1R61AG070265 (Lu)   09/30/20-08/31/21
NIH-NIA
Daily Engagement in Meaningful Activities Professional (DEMA-PRO) Intervention for Seniors with Subjective Cognitive Decline and Living at Home
In this pilot, we propose to adapt and test DEMA-Professional (DEMA-Pro), so it can be delivered in home health by a trained coach to enhance clinical outcomes (e.g., physical functioning).
Role: Co-Investigator

CDR-2018C3-14715 (Schwartz)   11/01/19 – 10/31/23
Patient-Centered Outcomes Research Institute
Measuring the Impact of Providing Personalized Risk Information to Patients and their Providers

The main objective of this application is to test whether providing patients and their providers with personalized messages about advanced colorectal neoplasm (ACN) risk results in higher screening uptake and higher decision quality, compared to an approach that does not utilize ACN risk.
Role: Biostatistician

1UL1TR002529-02 (Moe)   05/01/18 – 04/30/23
NIH-NCATS
Indiana Clinical and Translational Sciences Institute

To establish a new institute that facilitates clinical and translational biomedical research across the state of Indiana. This is an institute established by the CTSA to Indiana and Purdue Universities.
Role: Director, Biostatistics, Epidemiology, and Research Program.

1R18HS025943-01 (Perkins)   01/01/19 – 12/31/21
AHRQ
Purdue Univ. [AHRQ-PI: Snyder]
An Evaluation of the Spread and Scale of PatientToc From Primary Care to Community Pharmacy Practice for the Collection of Patient-Reported Outcomes

This research will advance understanding of the potential for health information technology to facilitate the sustained, meaningful spread and scaling of patient-reported outcomes collection from primary care practices to community pharmacies.
Role: Co-Investigator

W81XWH-14-20151 (McAllister)   07/29/14-08/31/21

U. S. Department of Defense
The NCAA-DOD Grand Alliance: Concussion Assessment, Research and Education (CARE) Consortium
This investigation is poised to address the true natural history of clinical and physiological recovery of sport related concussion, which has critical implications for improving safety, injury prevention, and medical care in athletes and military personnel.
Role: Co-Investigator

Completed Research Support (within the last 3 years)

IHS-1507-31333 (Rawl)   07/01/16 – 12/31/20
PCORI
Comparing Interventions to Increase Colorectal Cancer Screening in Low-Income and Minority Patients

The aims of the study are: 1) compare the effectiveness of two interventions designed to promote CRC screening – mailed tailored DVD versus them mailed tailored DVD plus telephone-based patient navigation – to each other and to usual care 2) examine age, race/ethnicity, sex and income as potential moderators of intervention effects, and 3) examine changes in knowledge and health beliefs (perceived risk, perceived benefits, perceived barriers, and self-efficacy) as potential mediators of intervention effects.
Role: Co-Investigator

1R01NR015789-02 (Robb)   07/06/16 – 05/31/20
NIH-NINR
Mechanisms of Active Music Engagement to Manage Acute Distress and Improve Positive Health Outcomes in Young Children with Cancer and Parents

The purpose of this two group randomized controlled trial is to identify behavioral, sociological, and psychological variables contributing to positive outcomes observed in previous AME studies (i.e., mediators) and identify for whom the intervention works (i.e., moderators).
Role: Co-Investigator

JoAnn Brooks, DNS, RN, FAAN
Evaluation of Health Related Quality of Life Mood Stages, and Fatigue Pre and Posttreatment for Esophageal Cancer
Reference: Prospective analysis of quality of life after surgical resection for esophageal cancer: Preliminary results - Brooks - 2002 - Journal of Surgical Oncology - Wiley Online Library

Janie Canty-Mitchell, PhD, RN
Quality of Life in African American Children with Chronic Conditions

Little is known about quality of life in African American children with chronic conditions. African American children have higher rates of morbidity and mortality than most other ethnic groups in the United States, yet are often underrepresented in clinical and pediatric research. Disparities in health outcomes may be linked to a variety of personal, family, and environmental stresses that influence quality of life in these children. Identifying factors that predict quality of life in African American children with chronic conditions may help to frame interventions, especially in critical areas of support: families, social services, health, mental health, juvenile justice, and schools. The specific aims of the proposed study are:
- To describe differences in quality of life between African American and Caucasian children with chronic conditions, taking social economic factors into account
- To identify child, family, and environmental factors associated with quality of life in African American children with chronic conditions

Janet Welch, PhD, RN, FAAN
Compliance in Hemodialysis Patients

When hemodialysis patients reduce their fluid intake, they prevent severe medical complications, reduce the risk of premature death, and improve quality of life. Despite these benefits 50-90% of hemodialysis patients do not adhere to fluid recommendations. This cross-sectional study sought to identify factors that differentiate those individuals who are adherent from those who are no adherent in a convenience sample of 147 adults. Individuals who were adherent to fluid guidelines experienced less thirst intensity, perceived more benefits, perceived fewer barriers, perceived the complications as more serious, and felt personally vulnerable to the complications of fluid non adherence. However, cognitive function, family functioning, family routines, self-efficacy, and thirst distress did not differentiate those who were fluid adherent from those who were non adherent.

Kathleen Russell, DNS, RN
Instrument Development to Measure Sociocultural Variations Related to Mammography Screening Among African American Women

Current health behavior models for predicting breast cancer screening do not adequately consider the sociocultural variables that may influence African American women. This specific aims of this study were to:
- Describe the sociocultural characteristics of the African American population relevant to breast cancer screening behavior.

- Develop an instrument to measure sociocultural factors likely to affect cancer screening behaviors in African American women
- Test the instrument for reliability and validity

Susan Rawl, PhD, FAAN
Predictors of Quality of Life After Treatment with Curative Intent for Colorectal Cancer

Colorectal cancer patients and their spouses differ in their ability to adapt to the physical and psychological demands of disease and treatment, with some being particularly at risk for severe and chronic decrements to quality of life. Identifying such persons early will enable health care providers to initiate preventive interventions before problems become entrenched.
A major aim of this pilot project was to investigate associations between bowel, sexual and urinary function, respectively, and global quality of life at six months and one year after treatment. In a sample of 34 patients and 24 spouse-partners findings included the following:
- Older patients and those who were more religious reported relatively higher quality of life.
- Participants who had stomas had poorer outcomes in general.
- Female partners, especially those who were employed, reported relatively greater disruption in role responsibilities.
- Clinicians have begun to recognize and attend to the psychological needs of cancer patients, including treatment of depression and anxiety. Results of this study indicate that greater attention to the psychological distress of spouses also is needed.

Rebecca Sloan, PhD, RNCS
Readaption of Spouses to End Stage Renal Disease

In the United Stated today, nearly 283,000 persons are experiencing end-stage kidney failure. For these individuals, the only hope for survival is through invasive dialysis treatments or kidney transplantation. Although much is known about the concerns, Stresses, and physical complications of these medical treatments for patients, very little is known about how the families of kidney failure patients experience these burdens. This study explores the experience of spouses of end-stage kidney failure patients who must return to dialysis after loss of a kidney transplant of after getting very close to a potential transplant opportunity, four interviews with each participant will be conducted over the first year of returning to dialysis therapy. It is anticipated that stages if readapting to dialysis can be identified and interventions to assist families of these patients in readjusting to the events can be developed. With this new knowledge, nurses will be able to construct patient/family education programs to support families in these situations.

Kathleen Hanna, PhD
Determination of Psychometric Properties of Diabetes Specific Scales to Measure Parents' and Adolescents' Decision Making and Support Related to Diabetes Management Roles and Responsibilities

Adolescence is an especially challenging time for parents and adolescents with type 1 diabetes. Adolescents must learn to manage their diabetes and a parent is to remain involved and yet help the adolescents become more independent. This study investigates how parents and adolescents make decision and help one another. Subjects and 100 adolescents with type 1 diabetes and their parents. Parents and adolescents are being asked to complete questionnaires on how they make decisions and support one another. The essential questions

to measure decisions and support are being identified as a basis for the development of a brief assessment instrument. These assessments will help guide parents and adolescents through this process of shifting responsibility for diabetes management.

Marsha Ellett, PhD, RN, CNE
Examination of Enteral Tube Placement in Children

When the gastrointestinal system is functional but a child cannot eat orally, feeding by a tube passed through the nose or mouth into the stomach is needed. When tubes are out of place, children can be harmed. This study tests different ways to determine where feeding tubes are positioned in the gastrointestinal tract to make tube feeding safer for children. In this study, the position of the tube is screened by:
- Measuring carbon dioxide
- Measuring tube aspirate for pH and bilirubin.

Actual tube position is determined by abdominal x-ray within 15 minutes of the bedside screening. An x-ray cannot routinely by obtained each time the position of the feeding tube needs to be known without a lot of expense and exposure of the child to radiation. The results of the screening procedures and the position of the tube on x-ray are compared to determine which of the beside screening methods provides the most accurate information

Tamilyn Bakas, PhD, RN, FAHA, FAAN
Quality of Life Among Caregivers of Aphasic and Cognitively Impaired Stroke Survivors

Stroke is the leading cause of disability in the United States and there are over 4 million stroke survivors alive today. Most stroke survivors require the help of family members in the home setting. The first few months after stroke are stressful for family members. The purpose of this study is to investigate how caring for the stroke survivor with speech or cognitive impairment as a result of their stroke. The telephone interviews address such topics as:
- How the caregiver's life has changed since the stroke
- Physical, social, and mental health of the caregiver
- Specific things that the caregiver does to help the stroke survivor
- Physical, emotional, and behavioral problems that the stroke survivor may have that are difficult for the family caregiver

Findings from this study will be used to develop ways to help family caregivers care for both themselves and their loved ones with stroke.

Susan (Bennett) Pressler, PhD, RN
Tailored Web Patient Education for Heart Failure Care

Heart failure is nearing epidemic proportions and there is a need for innovative approaches to care that facilitate learning and behavioral change in order to improve health outcomes. This article discusses the development and pilot testing of the PUMP UP program, a tailored computerized intervention, designed to improve 4 health outcomes. The development phases included evaluation of knowledge and design and computerization of the intervention. Pilot testing was completed with 12 patients recruited from primary medicine clinics. Patients completed a baseline telephone interview; follow-up data were obtained immediately after the intervention clinic visit and at 4, 8, and 26 weeks after the visit. Four of the 12 patients met the outcome of improved provider adherence to guidelines. Health-related quality of life scores improved at 26 weeks after baseline. The PUMP UP program was informative and feasible to deliver. It is now ready for testing in intervention studies with larger samples.

Angela McNelis, PhD, RN, ANEF
A Pilot Study of a Family Seizure Management Program, "Be Seizure Smart"

Children with epilepsy have high rates of mental health problems including poor self-esteem, depression, and behavior problems. They are almost 5 times more likely to have problems than children from the general population. Interventions are needed for children:
- To help prevent or reduce mental health problems
- To increase their ability to manage the seizure condition

The purpose of this 2-year study is to further develop and pilot test a psycho educational telephone and mail intervention, be seizure smart. Be Seizure Smart is designed to reduce concerns and fears and to improve knowledge about seizures. It is hypothesized that providing information and support to address parents and children's concerns and fears about seizures and increasing knowledge about seizures will lead to better outcomes in these children.

Sara Horton-Deutsch, PhD, CNS, RN
Decision-making Capacity and Quality of Life in Community-dwelling Older Adults with Cognitive Impairment

Modern medicines ability to prolong life is steadily increasing. However it is not always clear whether persons with cognitive impairment can make informed choices regarding treatment options. The purpose of this study is to investigate healthcare decision making in persons with mild to moderate cognitive impairment. Patients and their family caregivers will be asked to participate by:
- Discussing healthcare decisions they have made in the past year.
- Responding to hypothetical medical situations. Caregivers will be asked to choose the options they think the patient would make. Patients will be asked to recall their decisions on the hypothetical medical situations in one month.

Patient and caregiver responses to treatment options will be compared for consistency. Findings from this study will be used to learn about the ability of persons with mild to moderate cognitive impairment to make healthcare decisions over time. This research is important to ensure patients autonomy and self-determination as long as possible. It also encourages communication within families about healthcare decision making and promotes future healthcare planning.

Janis Gerkensmeyer, PhD, RN, APRN, BC
Quality of Life and Life Satisfaction Among Parents of Children and Adolescents with Mental Health Problems

Distress experienced by children with mental health problems and their families has created a health crisis in our country associated with many unmet service needs. Parents caring for children with serious mental health problems face tremendous challenges. We know relatively little, however, about the extent and nature of the stressors these parents face or how their quality of life and life satisfaction are affected. The purpose of this study is to examine the factors associated with the quality of life of parents caring for children with serious mental health problems. Findings from the study with help guide future healthcare interventions targeted toward improving parents quality of life and life satisfaction.

Patricia Ebright, PhD, CNS, RN, FAAN
Factors Affecting Pain Management Decision Making by Healthcare Providers and Adults with Rheumatoid Arthritis

Chronic, debilitating pain is often a major problem for persons with rheumatoid arthritis. However, both healthcare providers and those with the condition underutilize effective pain management strategies. Additional research is needed to understand:
- Factors that influence healthcare provider decisions about pain management for rheumatoid arthritis patients in actual care situations and
- Factors that influence delivery of pain management interventions by healthcare providers to rheumatoid arthritis patients in actual care situations.

The purpose of this 2 year study is to test research methods that may help to increase understanding of pain management decision making and delivery by healthcare providers to persons experiencing chronic pain from rheumatoid arthritis. This research is a first step in designing healthcare environments and education that support decision making and delivery in relation to effective pain management.

Janice Buelow, PhD, FAAN
Quality of Life and Psychosocial Care Needs of Children with Both Epilepsy and Low IQ and of Their Parents

Epilepsy is one of the most common neurological disorders in children, and between ¼ and 1/3 of children with epilepsy also have some degree of mental retardation. Despite the prevalence of this problem, little is known about the particular quality of life issues and psychosocial care needs of these children and their families. This pilot study is designed to identify the quality of life problems and psychosocial care needs of children with both epilepsy and low IQ and their parents. Parents and children will be interviewed to explore their perceptions related to these factors. The information obtained from this study will be a first step toward developing nursing interventions to help these children and their parents.

Cheryl Shore, PhD, RN
Bone Mass, Bone Turnover and Homocysteine Levels in Young Women on AEDs

Alterations in bone health have been discovered in a significant proportion of individuals taking antiepileptic drugs to control seizures, increasing their risk for fractures. While multiple studies have supported relationships between AED use and increased fracture risk, the mechanism(s) responsible for alterations in bone dynamics are elusive. Recently, homocysteine has been implicated as a factor promoting osteoporosis in studies of persons following stroke. Serum homocysteine levels have been shown to increase with initiation of AED therapy in youth with epilepsy. However, no studies have investigated the relationships among indicators of bone health and homocysteine in a sample of individuals with epilepsy. The purpose of this study is to determine the feasibility of investigating the relationships among bone mineral density, indicators of bone turnover, and homocysteine in young women who have epilepsy. If relationships between homocysteine and bone turnover and/or bone mineral density are demonstrated, prevention may involve B vitamin supplementation in addition to the current recommendation of calcium and vitamin D prescription.

The proposed study willl use a cross-sectional, correlational design. Ten women aged 18 to 30 will be recruited. Because this is a small feasibility study, the sample will be homogeneous. Measurements of bone mineral density, metabolic indicators of bone turnover, homocysteine levels, plus self report measures of diet and activity behaviors will be collected.

Relationships among the variables will be examined. Values for bone mineral density, indicators of bone turnover, and homocysteine level will also be compared to normative values.

The results of this study may lead to improvement in quality of life for people with epilepsy, allowing them to maintain seizure control while managing the risk for altered bone health, thus supporting the goal of "no seizures, no side effects". Within a public health context, the results of this study could lead to fewer people in the population at risk for osteoporosis. Fractures due to osteoporosis are currently more common than heart attack, stroke or cancer.

Seongkum Heo, PhD, RN
Improving Dietary Sodium Adherence, Symptom Burden, and Health-Related Quality of Life in Heart Failure

Non-adherence to dietary recommendations is an important antecedent of poor health-related quality of life (HRQOL) and high hospitalization and mortality rates in heart failure (HF). Patients' cognitive factors such as knowledge, perceived control, perceived barriers and benefits, and emotional factors such as depression affect dietary adherence. Many interventions have been provided to improve self-care behaviors including dietary adherence, HRQOL, and/or clinical outcomes. However, the studies have limitations due to one or more of the following reasons: 1) interventions not based on behavior theories or models; 2) interventions not based on the analysis of patients' dietary habits and barriers to following dietary recommendations; 3) no teaching about the connection between diet and diet-related symptoms and symptom management; 4) no comprehensive measurement of the impact of interventions on adherence, HRQOL, and clinical outcomes; and 5) limited impact of interventions on the outcome variables.

Janet Fulton, PhD, RN, ACNS-BC, FAAN
Measuring Oral Mucositis and Related Side Effects in Head and Neck Cancer Patients Receiving Radiation Therapy

Head and neck cancer, the fifth leading cause of cancer worldwide, accounted for approximately 3% of new cancers in the United States in 2007. The majority of these patients are treated with radiation therapy. Major barriers to improved care for these patients include lack of scientific evidence to support oral hygiene interventions and lack of clinically useful assessment instruments to guide clinical evaluation of mucositis and related side effects of treatment. Existing instruments focusing on physical measures are useful in multi-site clinical trial studies; however, these instruments are not adequate for measuring subjective symptoms and functional consequences of mucosal injury. The inability to measure all three domains - physical, functional and symptom - preludes determining incidence, monitoring individual outcomes, and developing new interventions. The purpose of this study is to develop an instrument to measure mucositis and related side effects across three domains of physical, functional and subjective symptoms as experienced by patients undergoing radiation therapy for head and neck cancer, to conduct a feasibility study of this new instrument with 5 - 10 patients, and as time permits conduct a pilot test of the instrument with up to 50 patients with head and neck cancers. Instrument development will use the process described by Lynn; item validity will be determined by using the content validity index method described by Waltz. Findings from the new instrument will be compared to the NCI Common Toxicity Criteria. Results of this study will contribute to the ability to adequately measure radiation treatment induced mucositis and related side effects experienced by persons with head and neck cancers. More precise measurement will help facilitate development and testing of interventions for this high-risk population.

Diane Von Ah, PhD, RN
Cognitive Dysfunction and its Impact on Quality of Life in Breast Cancer Survivors

Among female breast cancer survivors (BCS), cognitive impairment is a prevalent, disruptive, and potentially debilitating symptom. Although cognitive impairment after cancer has been identified as a national research priority, only a few studies have attempted to understand its' impact on quality of life issues for BCS and none have used a mixed method approach to explore the impact of cognitive impairment on functional outcomes and quality of life or explored from the BCS's perspective ideas to manage and cope with this debilitating symptom. Thus, the purpose of this proposal is to address a gap in the literature by providing a richer and more complete understanding of BCS experiences related to perceived cognitive impairment and its impact on quality of life after breast cancer diagnosis and treatment. This study will build on an existing Robert Wood Johnson Foundation (#64194) funded and Institutional Review Board (IRB# 0811-658) approved study. Participants who are enrolled in the parent study and have completed objective neuropsychological testing and quantitative subjective reports regarding their cognitive functioning will be eligible for the study. This mixed methods study will occur in two phases: Phase 1 will involve completion of quantitative questionnaires regarding overall functional status and quality of life to be completed by the BCS prior to the qualitative interviews. This will allow the participants an opportunity to reflect upon what extent breast cancer diagnosis- and treatment-related cognitive deficits have impacted the survivor's daily functioning and quality of life. Phase 2 will involve the completion of qualitative interviews exploring the impact of cognitive impairment on functional outcomes and quality of life, as well as, explore from the BCS's perspective potential treatment options. Study aims are to: (1) Identify BCS's perspectives regarding the impact of cognitive impairment on functional outcomes (relationships, work ability, etc.) and quality of life after breast cancer diagnosis and treatment; and (2) Explore what types of interventions BCS have used to address their cognitive impairment after breast cancer diagnosis and treatment. Functional status and Quality of life will be measured by the 36-Item Short-Form Health Survey (SF-36) and Quality of Life-Cancer Survivors (QOL-CS) and open-ended semi-structured questions. Quantitative data will be analyzed using descriptive statistics, qualitative analyses including the identification of themes will be used to summarize the qualitative interview, and a comparative analysis of qualitative and 1uantitative findings will be used to identify commonalities and differences between the subjective qualitative and quantitative reports. This important study will broaden our understanding of the impact of cognitive impairment on functional outcomes and quality of life for BCS. Findings of this study will be used to support the development and testing of new treatment strategies for cognitive impairment in BCS, a group that disproportionately incurs this debilitating symptom.

Ukamaka M. Oruche, PhD, RN, PMHCNS-BC
Needs and Concerns of Family Members of Adolescents with Disruptive Behavior Disorders

Families of children with serious emotional disturbances (SED) face a number of challenges. SED signifies the presence of a diagnosable mental, behavioral, or emotional disorder which results in a functional impairment that substantially interferes with the child's role or functioning in family, school, or community activities.[1] Mental disorders include attention deficit hyperactivity, oppositional defiant and conduct disorders; depression with associated suicide risks; anxiety disorders; bipolar disorders; and schizophrenia.[2] Rates of SED double in adolescence, between ages 12 and 13 years, with increased incidence of functional

impairments as the child ages.[3-5] Adolescents with SED are faced with the development task of individuating from their families while dealing with the stress of their mental illness.[6]

The families of adolescents with SED do not often receive supportive services in the mental health system. Yet, research shows that if family members are not provided services and supports needed to deal with the challenges of the adolescent's illness, the adolescent's recovery is impaired.[7,8] Caregivers of children with mental health problems emphasize that treatment should include the whole family[9,10 11] but limited information is available about the needs of families of adolescents with SED. Research that has been done on these families has focused almost exclusively on the experiences of one family member, most often the mother,[11,12] and virtually nothing is known about the experiences of fathers and siblings.[12] Understanding the experiences of multiple family members of adolescents with SED from each family member's perspective is needed to develop effective family-focused interventions.[7,13] Such interventions could increase access and use of supportive services, improve the quality of life of all family members, and enhance their efforts in providing care and support for the adolescent.

The <u>purpose of this pilot qualitative descriptive study</u> is to describe the experiences and needs of multiple family members of adolescents with SED. Specific aims are:
<u>Aim 1:</u> To describe how multiple family members (parents or guardians, siblings, and other significant extended family caretakers) perceive their experiences of living with an adolescent with SED.
<u>Aim 2:</u> To describe the family members' perceived needs for support in regards to their own concerns or in their efforts to support the adolescent with SED.
<u>Aim 3:</u> To describe the family members' reported use of any health-care or social services related to the adolescents' illness.
<u>Aim 4:</u> To describe the family members' perceived need for health-care or social services related to the adolescents' illness.
<u>Aim 5:</u> To describe what kinds of support that the adolescent with SED would like from their families and health care providers.

Wendy R. Miller, PhD, RN, CCRN
Development and Psychometric Testing of the Adaptational Outcomes in Epilepsy Scale

Epilepsy is a chronic disorder necessitating independent and complex self-management. It is well known that those self-managing chronic diseases often experience undesirable alterations in adaptational outcomes—somatic health, social functioning, and well-being—when compared with those without chronic diseases. While relatively less is known about the specific alterations in adaptational outcomes that occur in persons with epilepsy, findings from recent research studies indicate that those with epilepsy experience, or are at risk for experiencing, decrements in adaptational outcomes. However, knowledge regarding changes in these outcomes *resulting from having and managing epilepsy* remains lacking. While several tools, some of them epilepsy-specific, measure these adaptational, or similar, outcome variables, no tool measuring *changes* in these outcomes that occur due to being diagnosed with and self-managing epilepsy exists. There is a need for a situation-specific instrument measuring changes in adaptational outcomes that occur as a result of being diagnosed with and self-managing epilepsy.

The purpose of the proposed study is to develop and psychometrically test an instrument, the Adaptational Outcomes in Epilepsy Scale (AOES), measuring changes in adaptational outcomes in adults with epilepsy since the time of diagnosis.

Janice M. Buelow, PhD, RN, FAAN
Social Cognitive Functioning in Early Adolescents with Chronic Epilepsy

Psychosocial problems such as social isolation and poor social competence are significant in adolescents with chronic epilepsy [1-6] and can affect long-term outcomes important for young adulthood [7-9]. Most research has focused on adolescents' high rates of mental health/behavioral problems as well as their neuropsychological and academic problems. Though social isolation and poor social competence, indices of social cognitive functioning, are widely reported, they are most often attributed to social stigma and having a seizure in front of others [10, 11]. Few studies have examined the role that social cognitive functioning plays in these social problems. Social cognitive functioning is broadly defined as the cognitive processes necessary to plan, understand, and initiate appropriate social interaction. Social cognition is a developmental process that begins in childhood and continues through adolescence [12, 13]. Having chronic epilepsy may affect the development of social cognitive functioning because seizures can affect normal development in areas in the frontal and temporal lobes, which is where seizures commonly arise [14-16]. Despite the immediate and potential long-term effects of social cognitive dysfunction, there have been few studies exploring the role of social cognitive functioning in adolescents with epilepsy [17]. In addition, no reported studies to date have explored the relationships between social cognitive functioning and adolescent psychosocial outcomes that are important for successful functioning as adults. These outcomes include behavior/mental health, self-concept, responsibility for the management of the condition, and satisfaction with social relationships. We are including responsibility for management of the condition because it is an illness-specific outcome potentially related to social cognitive functioning that is an important aspect of successful functioning as an adult. In the proposed pilot study, we will investigate social cognitive functioning, factors influencing social cognitive functioning, and the relationships between social cognitive functioning and psychosocial outcomes in adolescents with epilepsy.

Susan E. Hickman, PhD
The Quality of POLST Decision-Making: A Pilot Feasibility Study

Patient treatment preferences are traditionally communicated using patient-generated advance directives or medical orders narrowly focused on cardiopulmonary resuscitation (CPR) status. Unfortunately, these traditional practices are largely ineffective at altering end-of-life treatments.[1,2] The Physician Orders for Life-Sustaining Treatment (POLST) Program was developed to overcome the limitations of traditional practices for communicating treatment preferences. The centerpiece of the POLST program is a medical order form that documents preferences for life-sustaining treatment in a format that is transferrable across care settings. It is designed for persons with advanced chronic progressive disease or frailty and is used extensively in the nursing facility setting. The POLST Program facilitates documentation of a range of treatment preferences [3,4] and prevents unwanted hospitalizations to ultimately help ensure the best possible quality of life.[2,5,6,7] *Despite its widespread and growing use, there is minimal evidence about the quality of POLST decision-making.* Further exploration into this topic could shed light on the broader issue of quality of decision-making in patients with serious illness, an area that has been identified as a national priority in the fields of decision science and palliative medicine.[8] Quality is a particularly important issue for high-stakes preference-sensitive decisions, such as decisions to accept or decline potentially life-sustaining treatments,

that impact quality of life. Quality decision-making requires a well-informed patient who is satisfied with their level of involvement in the decision-making process and experiences low levels of decisional conflict.[9-11] The result should be decisions that are consistent with patient preferences[9] and high levels of decision satisfaction.[12] Surprisingly, there are no published studies addressing patient or surrogate preferred involvement in the POLST decision-making process, knowledge, decisional conflict, or decision satisfaction. There is only one retrospective, chart review study that assessed whether POLST orders align with patients preferences and goals, but the small sample size (n=7) greatly limits its generalizability.[13] Furthermore, there are no studies to evaluate how best to facilitate high quality POLST decision-making.

Julie L. Otte, PhD, RN, OCN
Understanding Sleep Disorders in Breast Cancer Survivors: Feasibility and Acceptability of Study Procedures

Breast cancer survivors (BCS) represent the largest group of female cancer survivors and are two times more likely to report poor sleep compared to women without cancer. The specific sleep disorders that are experienced by cancer survivors are unknown. These sleep disorders can occur singly or in combination and can include insomnia, sleep related breathing disorders, hypersomnia, circadian rhythm disorders, parasomnias, sleep related movement disorders, isolated symptoms, and other non-specified disorders. Poor sleep is considered a long-term problem commonly experienced even by BCS who are 10 years post-treatment. Sleep is vital to all human functioning and encompasses complex physiological and behavioral processes; disruption in one or more of these processes can lead to many different types of sleep disorders. Sleep disorders are known to cause poor healing, decreased cognitive functioning, decreased work productivity, increased safety issues, poor relationships, and increased health care costs. The current methodology for studying sleep within and outside of the cancer literature is limited to defining symptoms of poor sleep. However, these methods neglect the larger issue of assessing specific types of sleep disorders underlying such symptoms. Not knowing this information has had a major impact on how the problem is treated. Each sleep disorder requires a different intervention; yet, most intervention studies in BCS have used behavioral treatments that target a generic form of insomnia as the underlying sleep disorder with poor efficacy of those treatments. Although behavioral treatments for insomnia are effective in sub populations with certain types of insomnia, these treatments will not be effective for insomnia that is occurring with a concurrent sleep disorder such as sleep apnea. Identifying sleep disorders in BCS reporting symptoms of poor sleep quality is essential so that appropriate, tailored interventions can be identified and tested.
No previous studies have examined sleep disorders using a structured interview approach including biomarkers of sleep disorders. Therefore, the purpose of this pilot study is to evaluate the feasibility and acceptability of the parent study procedures by evaluating all steps of the parent study procedures including; recruitment, screening, consenting, scheduling of interviews, completion of interviews, data collection, data entry, problems establishing prevalence of sleep disorders, and acceptability by BCS. This pilot data will provide the necessary data to support the parent American Cancer Society study and provide support for the resubmission of an NINR R01 proposal. The hypothesis is that using a one-time, structured, in-person interview and subsequent blood draw for biomarkers of sleep disorders will be feasible and acceptable to BCS who report sleep disturbances 1-10 years post-treatment.

Carol Shieh, DNSc, RNC-OB, MPH
Self-monitoring of Lifestyle Behavior Related to Weight Gain in Pregnant women

Excessive gestational weight gain in pregnant women can lead to many maternal and infant adverse outcomes such as cardiovascular and metabolic disorders as well as surgical manipulation for labor. Lifestyle management of nutrition and physical activity is the key to excessive gestational weight gain prevention. Self-monitoring along or with at least one of four self-regulatory strategies (prompt intention, goal setting, review of behavior goals, and feedback) has been shown to have the most influential effect on healthy eating, physical activity, and weight management. Recent research further suggests that including environmental determinants, in addition to cognitive factors, would increase the effect of self-monitoring on health behavior change. Our long-term goal is to develop a goal-driven and progressive self-monitoring intervention that involves cognitive and environmental determinants of healthy eating and physical activity in order to promote adherence to the Institute of Medicine's gestational weight gain recommendation, especially among overweight or obese pregnant women. The overall goals of this proposed pilot study are (1) to assess the feasibility of a prototype self-monitoring intervention for weight gain, food intake, and walking in overweight or obese pregnant women and (2) to collect qualitative data from study participants about their views of physical and sociocultural barriers to and resources for self-monitoring, lifestyle change in nutrition and physical activity, excessive gestational weight gain prevention, and study participation. In our proposed study, 20 overweight/obese pregnant women will be instructed on how to perform eight weeks of self-monitoring of weight gain, food intake, and walking, progressing from monitoring one of the three variables to all three at once. Feasibility data about self-monitoring compliance and attrition will be collected. Patient-centered views about barriers to and facilitators of self-monitoring, lifestyle behavior change, excessive gestational weight gain prevention, and study participation will also be collected and used for refining the self-monitoring intervention. Public Health Relevance: Healthy eating and physical activity are national health goals addressed in Healthy People 2020. Using self-monitoring as a strategy to reinforce healthy eating and physical activity, as proposed in our study, has potential impacts not only on the pregnant woman's gestational weight gain but also on her overall pregnancy health and that of her baby. Our study reflects the National Institute of Nursing Research's health promotion and disease prevention strategic goal.

Rhonda Schwindt, DNP, RN, PMHCNS-BC
Tobacco Cessation Training for Health Professional Students Working with Seriously Mentally Ill Patients Who Smoke

Persons living with a serious mental illness represent an especially vulnerable and disadvantaged subgroup of smokers. Compared to those in the general population, they smoke more, die younger, and suffer disproportionately from cardiovascular disease, diabetes, stroke, and cancer, all diseases and conditions directly associated with, and exacerbated by, smoking. Despite strong evidence that tobacco cessation counseling by a health professional can approximately double patients' odds of quitting, clinicians across disciplines are reluctant to offer these individuals effective means by which to quit smoking. This disinclination is due, at least in part, to inadequate tobacco cessation training during degree education. The purpose of this 2-phase pilot project is to develop and assess the preliminary impact of an interprofessional tobacco education program (ITEP) on the perceived self-efficacy, self-reported counseling abilities, simulated learner competence, and learner satisfaction of nursing, pharmacy, and social work students. In phase 1, we will: (a) modify a well-tested, widely disseminated, existing PowerPoint-based curriculum into a multimedia web-based intervention; (b) design a faceto-

face training session using an interprofessional education (IPE) framework; and (c) develop Objective Structured Clinical Examinations (OSCEs) with tobacco-specific standardized patient interviews to assess simulated learner competence. In phase 2, we will pilot test the intervention for learner satisfaction and preliminary effects using a one-group, pre-test-post-test design among nursing, pharmacy, and social work students (n=10 each; 30 total). The ITEP will augment the standard tobacco cessation coursework currently offered at the respective institutions. All participants will complete pre- and post-training surveys and posttraining IPE OSCEs. In addition, qualitative interviews will be conducted with a volunteer subset of 9 students (3 from each discipline) to assess learner satisfaction. Data will be analyzed using descriptive statistics, correlations, paired t-tests, and qualitative analysis techniques. The proposal is responsive to the National Institute of Health's research priority on prevention and cessation of tobacco use and tobacco-related health disparities in diverse populations, and to the Substance Abuse and Mental Health Services Administration funding opportunities.

Janet Welch, PhD, RN, FAAN
Understanding the Care Seeking Behaviors of People with Chronic Kidney Disease

There are currently 26 million Americans with chronic kidney disease (CKD) who have an increased risk for cardiovascular disease and higher hospitalization rates and health-care costs. Unfortunately, there are limited data about where or how often these individuals seek care and how care seeking varies across the stages of CKD. The purpose of this retrospective descriptive study is to describe CKD care-seeking behaviors, defined as care "encounters" with the health care system. Patients with Stages 1 – 5 CKD will be identified in two existing de-identified claims databases obtained from Teladoc, a nationwide provider of physician telephone consult services. These two databases contain more than one million claims records from over 15,000 subscribers. All patients will have a minimum of 12 months of continuous enrollment to be included in the study. Data analyses will include descriptive statistics examining variation in care seeking behaviors by stage of CKD as well as segment analysis (how care seeking varies year over year).

Sheri Robb, PhD, MT-BC
Active Music Engagement to Manage Acute Distress and Improve Positive Health Outcomes in Young Children Undergoing HSCT and Parents

Palliative care is a comprehensive system of care that provides comfort care, pain and symptom management, as well as psychosocial support to patients/families with potentially life-threatening or chronic illnesses. Emotional distress experienced by parents and young children undergoing hematopoietic stem cell transplant (HSCT) for cancer is a prevalent and persistent problem that impacts parent-child interaction, family functioning, and quality of life. In the longer-term, this acute emotional distress is related to traumatic stress symptoms after treatment ends. These families require palliative care interventions to manage acute treatment distress and prevent psychosocial problems during survivorship; yet no family-based, distress management interventions have simultaneously addressed the interrelated needs of parents and young children during HSCT. For young children, play is a means for working through and managing stressful events. Music-based play interventions are a particularly promising intervention for parent/child distress because music: 1) is a naturally occurring parent-child activity; 2) provides structure to support parent-child interactions during stressful hospitalizations; 3) positively influences mood; and 4) is easily integrated into family routines. Our previous research found that an Active Music Engagement (AME) intervention delivered by a credentialed music therapist reduced emotional distress in young children hospitalized for 3 day in-patient chemotherapy, with additional data about a modified intervention (AME+P) to manage both

parent/child distress. However, the AME+P has not been evaluated in the HSCT treatment setting and our team has identified HSCT as a treatment period where the intervention may be most beneficial to children/parents due to longer hospitalization (3-6 weeks) and higher levels of treatment-related distress. Here we propose a two phase pilot study. In phase 1 (months 1-2) we will translate the AME+P intervention protocol for HSCT, taking into account patterns of symptom distress and the HSCT treatment trajectory. This will be done in consultation with our physician and nurse co-investigators. We will also develop training procedures for interveners and treatment fidelity checklists. In phase 2 (months 3-10) we will determine clinical feasibility of the proposed study activities/timelines in the areas of recruitment, planned evaluations, and intervention delivery. These data, in combination with our previous studies, will allow us to develop a competitive multi-site R01 application to: 1) test AME+P efficacy during HSCT; 2) analyze implementation cost; and 3) examine AME+P intervention for prevention of traumatic stress in survivorship.

Wendy Miller, PhD, RN, FAAN
Pilot and Feasibility Testing of the Telephone Assessment and Problem Solving (TAPS) Intervention in Older Adults with Epilepsy

Background: Older adults are the population most affected by epilepsy, a chronic disease that requires lifelong self-management. Despite the high prevalence and incidence of epilepsy in persons aged 60 years and older, there are no published interventions designed to improve patient-centered outcomes of older adults with epilepsy. The purpose of the proposed pilot study is to test the feasibility, satisfaction, and initial efficacy of the Telephone Assessment and Problem Solving (TAPS) intervention, a theory-based and patient-centered intervention designed to improve outcomes in older adults with epilepsy. The TAPS intervention is meant to target proximal (self-efficacy, disease knowledge, and multi-level problem solving) and distal (cognitive, affective, and physical symptoms, epilepsy-related life changes, and resource utilization) outcomes.
Methods: A longitudinal, three-group experimental design is proposed. Older adults with epilepsy will be recruited from the Indiana University Neuroscience Center, and will then be randomly assigned to an intervention, attention control, or usual care group. Each group will be comprised of 20 participants. Participants in the intervention group will receive four bi-weekly intervention calls delivered by trained Registered Nurse interveners. Attention control group participants will receive an informational binder, and usual care group participants will receive neither phone calls nor a binder. Satisfaction and outcome data will be collected from all participants at various time points. Descriptive statistics will be utilized to describe participants' satisfaction with intervention and attention control activities, and ANOVA and Cohen's d will be used to evaluate group differences and to estimate effect sizes.
Impact: The proposed study is aligned with recommendations from both the Institute of Medicine and the American Geriatrics Society. Execution of the proposed study will address an important gap in the literature regarding the improvement of patient-centered outcomes in older adults with epilepsy. Results rendered from this pilot study will directly inform a New Investigator R01 application to the NIH (NINR) to be submitted in October of 2015, in which the principal investigator will propose a replication of the study with a larger and more diverse sample.

Rebecca Ellis, PhD, RN
Patients' Perceptions of Healthcare Provider Communication and Understanding of Prescribed Medications

The Centers for Medicare and Medicaid Services (CMS) Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey aims to put patients first by publicly reporting patients' perceptions of their hospital experience and of their ability to care for themselves after discharge. Managing medications after discharge is one such self-care task and misunderstanding of medications can lead to adverse drug events following hospitalization. One factor likely affecting how well prepared patients are to manage their medications post-hospitalization is the patient's perception of the quality of healthcare provider communication (verbal and nonverbal) during inpatient hospitalization. HCAHPS questions assess patient perceptions of healthcare provider communication while in the hospital, how well they understood their new medications while in the hospital, and how well they understood all of their medications at discharge. The **purpose** of this analysis of national HCAHPS survey data is to examine relationships among these three factors. The **specific aims** of this study are to 1) describe levels of and variation in patient perceptions of the quality of healthcare provider communication, patients' knowledge about new medications while in the hospital, and their discharge medication knowledge; 2) describe the relationships among these variables; and 3) evaluate medication knowledge while hospitalized as a mediator of the relationship between healthcare provider communication and discharge medication knowledge. Data analysis will be performed at two levels: (1) the hospital level using national HCAHPS datasets from over 3,000 acute care hospitals and (2) the patient level using IU Health HCAHPS data. Findings will be disseminated in two separate manuscripts. Understanding the relationships among these concepts will provide foundational information for future development of interventions aimed at healthcare providers so they are better able to communicate and deliver patient-focused, respectful, and skilled medication management information. The proposed study leverages existing large datasets and the Indiana University Nursing Learning Partnership to continue this important research collaboration and, more immediately, translate findings to build a program of research to improve clinical care.

Miyeon Jung, PhD, RN, FAHA
Feasibility study: Development of Natural Restorative Environment Intervention with Virtual Reality to Improve Attention

Heart failure (HF) is a prevalent chronic illness that affects 5.7 million American adults and has a 50% 5-year mortality rate.[1] Moreover, 24-50% of HF patients have cognitive impairment,[2-4] with attention being one of the most affected domains, possibly because of hypoxia and increased attentional demands from complex self-management regimen (e.g., medications, dietary restrictions).[5-7] Attention is a foundational cognitive process required for initiating and completing activities successfully.[8] In HF, impaired attention leads to inadequate self-management, which is associated with mortality, hospitalizations, and diminished quality of life.[9,10] Past studies have shown that attention can improve with theoretically based interventions using natural restorative environment (NRE), for example, walking in the park among children with attention-deficit hyperactivity disorder,[11] engaging in nature activities among women with breast cancer,[12] and viewing nature pictures among healthy adults.[13,14] Attention Restoration Theory guiding NRE interventions proposes that attention can be refreshed by interacting with nature, which provides rest to attentional networks by decreasing the need for directed attention.[15,16] Directed attention is effortful and has a key role in inhibiting distractions and regulating cognitive control of information.[8,13] Although attention is impaired in HF and is critical to self-management, little is known about interventions to improve HF patients' attention.

Rebecca Ellis, PhD, RN
Development of InterACT-Intervention to Promote Medication Adherence and Blood Pressure Control in Chronic Kidney Disease

One in every three adult Americans has high blood pressure, which contributes to morbidity, mortality and is associated with progression of chronic kidney disease (CKD). Despite the availability of medications to lower blood pressure and reduce the burden of hypertension, nonadherence to dosing regimens remains a problem for as many as 74% of people with CKD. Patients are often unaware of the variability in their medication taking and timing in implementing dosing regimens, which limits therapeutic effectiveness. Interventions such as pillboxes and personalized feedback on adherence behavior can improve adherence; however, to date, the ability to provide this feedback in real time is lacking. Capitalizing on intervention components such as pillboxes, we propose to develop an intervention (InterACT) that uses a wireless pillbox to automatically track medication taking and timing and provide this feedback via a connected smartphone to enhance medication self-regulation and improve blood pressure control. The **purpose** of this pilot study is to develop the technology and intervention content and test in order to gather preliminary data for a larger randomized controlled trial. **Specific aims** are to (1) describe patients' perspectives of what InterACT prototype design aspects will enhance medication taking and timing adherence; (2) develop InterACT technologies consisting of the 7-day wireless pillbox and connected smartphone app, intervention components, and study materials with input from patients and CKD experts; (3) evaluate the usability and acceptability of InterACT; and (4) test the feasibility of implementing the mHealth technologies in the home environment to deliver InterACT. The samples for Aim 1 will consist of 30 participants with concurrent comorbid hypertension and chronic kidney disease, reporting nonadherence, a group for whom medication management is particularly salient. For Aims 3 and 4, we will enroll 16 participants with random assignment of 10 participants to Aim 3 and 6 participants assigned to Aim 4. For Aim 1, we will hold a series of audio-recorded focus groups. For Aim 2, we will work with patients (n=5) and clinical experts (n=2) to design and develop the smartphone feedback dashboard and text messages that take into account information shared by patients during focus groups and develop study materials for the larger planned intervention study. For Aim 3, we will conduct a series of usability evaluations to iteratively test and refine InterACT in a controlled laboratory setting. For Aim 4, we will test InterACT in the home environment to determine feasibility. Findings from this pilot study will position our team to conduct a subsequent randomized, controlled trial.

Diane Von Ah, PhD, RN, FAAN
Home Based Cognitive Training Program for Breast Cancer Survivors Study

For millions of cancer survivors, cognitive impairment is a prevalent, severe, and persistent problem that is associated with other symptoms (depressive symptoms, anxiety and fatigue), poorer work ability, and poorer quality of life. Available evidence, including work by our own group, suggests that cognitive training may be a viable treatment option. However, to date, these studies are limited as none have been conducted in the home and therefore, fail to address the transferability of these empirically based cognitive training programs to general practice. **Therefore, the purpose of this translational research is to** conduct a home based single-blind, randomized controlled trial to test the feasibility, satisfaction, and preliminary efficacy of cognitive training compared to attention control in breast cancer survivors (BCS) as well as to explore potential biomarker of intervention effects. Specific aims are to: (1) examine the feasibility (facilitators and barriers) and satisfaction of the computer-based cognitive training program; (2) test the preliminary efficacy of cognitive training on improving cognitive performance (memory, processing speed, attention, working memory, executive function) over

time compared to attention control; (3) evaluate cognitive training effects on associated outcomes compared to attention control; and (4) explore the effect of computerized cognitive training on serum brain derived neurotrophic factor (BDNF) over time compared to attention control. BDNF is widely distributed in the brain, plays a crucial role in neuroplasticity and has been observed to correlate with cognitive function in cancer patients. A total of 68 eligible BCS will be stratified by age (<40 and > 40) and then randomized to computerized cognitive training or attention control. A blinded and trained tester will perform data collection and neuropsychological testing at two time points: baseline prior to intervention (T1) and immediately post-intervention (T2), and 6 months post-intervention (T3). Feasibility and satisfaction will be assessed through objective indicators (study adherence, completion rate) and self-report (facilitators, barriers, and perceived satisfaction) and cognitive performance will be assessed through objective neuropsychological tests of memory, processing speed, attention, working memory, executive function assessed over the phone. In addition, we will measure the effects of cognitive training on self-report measures of perceived cognitive function, associated symptoms (depressive symptoms, anxiety and fatigue), perceived work ability, and quality of life. Data will be analyzed using descriptive statistics and a general linear mixed model (GLMM). Simple main effects analyses will be used to follow up statistically significant interactions. **This research innovatively builds on our previous research by:** (1) translating findings from the laboratory to the home setting and importantly seeks to identify facilitators and barriers of intervention use; (2) addresses limitations of previous trials (uses an attention control rather than a no-contact or wait-list control), (3) examines cognitive training effects on real-life outcomes such as associated symptoms, perceived work ability and quality of life; and (4) will be the first study in cancer survivors to explore levels of BDNF as a potentially sensitive outcome measure of intervention effects over time compared to attention control. Findings from this study will provide necessary information about the feasibility, satisfaction and preliminary efficacy of the home based cognitive training on memory performance and processing speed as well as its effects on associated outcomes in BCS. Positive results will lead to a larger, full-scale study to determine efficacy and build evidence-based treatment for clinicians to use in treating BCS with cognitive impairment.

Chen Xiao Chen, PhD, RN
Phenotypic Characterization of Dysmenorrhea in Female Adolescents and Young Adults

Dysmenorrhea is a highly prevalent pain condition and a risk factor for developing other chronic pain later in women's life. Although dysmenorrhea is characterized by pelvic pain occurring before or during menstruation, significant inter-individual variablility exists among women in terms of pelvic pain severity, the number of painful sites, and co-occurring gastrointestinal symptoms. Our research team was the first to characterize these inter-individual variabilities into three distinct dysmenorreha symptom phenotypes. Improved phenotypic characterization is a prerequisite for precision treatment. The purposes of the proposed study are to further characterize symptom-based dysmenorrhea phenotypes identified previously by our team and to biobank gut and vaginal microbiome samples for future analyses. In this prospective longitudinal study, trained research staff will recruit and follow-up 60 female adolescents and young adults from adolescent medicine primary care and gynecology clinics. Participants will be followed for three menstrual cycles. These participants will answer questionnaires on dysmenorrhea symptoms, psychosocial characteristics, medication use, and provide vaginal swabs and stool for future microbiome assays. Data will be checked for missingness, and analyzed using descriptive statistics and mixed-effects models. Findings will provide feasibility, proof-of-concept data, and biobanked samples to support external funding applications to generate the science to improve precision dysmenorrhea treatment.

Eileen Hacker, PhD, RN, FAAN
Phenotypic Characterization of Persistent Fatigue in Allogeneic Hematopoietic Cell Transplantation Survivors

Allogeneic hematopoietic cell transplantation (aHCT), a potentially curative treatment for hematologic malignancies, is associated with significant mortality and long-term morbidity, including persistent fatigue. Persistent fatigue is one of the most frequent and life-altering symptoms associated with aHCT survivorship. A critical need exists to illuminate the biobehavioral components of persistent fatigue through phenotypic symptom characterization and discovery of associated biomarkers to inform interventions and treatment decisions. Research identifying co-occurring components of persistent fatigue in aHCT survivors and potential mechanistic pathways using carefully selected comparison groups is limited. This study will phenotypically characterize persistent fatigue in aHCT survivors, compare the temporal dynamic relationship between fatigue and physical activity in real-time, and discover potential inflammatory and oxidative stress biomarkers using a carefully selected control group (aHCT survivors with occasional tiredness). Clearly demarcating the differences between persistent fatigue that requires treatment and occasional tiredness, a normal biological phenomenon, is vital for phenotypic symptom characterization and sets the stage for intervention development. Data will be collected using: (1) computerized real-time assessments of fatigue measured eight times per day over seven days; (2) objective, real-time assessments of physical activity and sleep over seven days using wrist actigraphy; (3) patient-reported assessments of fatigue, sleep disturbances, emotional distress, and cognitive function; (4) computerized objective assessment of cognitive functioning (sustained attention, memory, and executive function); and (5) biological measures. The specific aims are:

Aim 1: To characterize the phenotype of persistent fatigue in aHCT survivors (n = 14) compared to aHCT survivors with occasional tiredness (n = 14). Hypothesis: Allogeneic HCT survivors with persistent fatigue will have significantly lower levels of physical activity, worse sleep, elevated emotional distress, reduced cognitive functioning, and altered biological measures compared to aHCT survivors and age- and gender-matched healthy controls with occasional tiredness.

Aim 2: Using real-time technology over seven days, compare the temporal, dynamic relationship between real-time fatigue and physical activity in aHCT survivors with persistent fatigue (n = 14) compared to aHCT survivors with occasional tiredness (n = 14). Hypothesis: Greater real-time fatigue precedes reductions in the subsequent 30, 60, and 120 minutes of physical activity in all three groups.

Aim 3: To identify the inflammatory and oxidative stress biomarkers associated with persistent fatigue compared to occasional tiredness in aHCT survivors and healthy controls (exploratory aim).

Kelly Wierenga, PhD, RN, FAHA
Emotion Regulation Intervention to Sustain Physical Activity in Rural-Dwelling Women and Men after Myocardial Infarction

Subject/population: This application is focused on improving secondary outcomes for first-time myocardial infarction (MI) survivors living in rural Indiana. It is critical to optimize effective cardiac rehabilitation programs to sustain participants' moderate to vigorous physical activity (MVPA) that may be negatively influenced by emotional distress common in this population. Specific Aim: Evaluate early preliminary efficacy of eMotion to improve MVPA (primary outcome) and secondary outcomes of physical function and performance, symptom improvement, and health related quality of life among rural dwelling adults enrolled in cardiac rehabilitation after a first MI (n=60).

Research Design: A 3-group, randomized, controlled pilot study will evaluate preliminary efficacy of a nurse led, theoretically based emotion regulation intervention (eMotion) to improve MVPA among a vulnerable group of survivors of MI living in rural areas of Indiana. Healthy living active control and eMotion conditions will be remotely delivered weekly for 10-weeks with asynchronous audio-visual content and individual synchronous weekly nurse video chats. Instruments: Actigraphy, participant surveys, psychological and cognitive tasks, and medical chart review.

Procedure: The 10-week eMotion intervention will be delivered to adults remotely alongside cardiac rehabilitation to sustain improvements in minutes of MVPA after cardiac rehabilitation ends. It will be compared to a healthy living attention control health education intervention matched in time and delivery mode and usual care. If efficacious, the eMotion intervention will provide a scalable and accessible treatment for individuals recovering from an MI that can improve emotion regulation and other cognitive mechanisms supportive of improved MVPA, as well as improve physical function and performance, physical and emotional symptoms, and health-related quality of life. Further, in this pilot testing we will examine early evidence that this revised program improves MVPA in rural MI survivors in preparation for a June 2021 NIH funding application.

Kelly Wierenga, PhD, RN, FAHA
Predictors of COVID-19 Self-management and Quality of Life among US Adults

Project Summary
With over 50,000 fatalities, the US is now reporting the highest number of deaths globally from COVID-19. Our interdisciplinary team has preliminary evidence from 1,013 US adults (mean age 42.1 ± 14.8, 81% women, 93% reported race as White, 50 states represented) which suggests that predictors in our preliminary study framework (see Figure 1) are associated with poorer adherence to physical distancing recommendations. Adhering to self-management behaviors, such as physical distancing and symptom reporting, is required for optimal slowing of transmission, yet is complicated by psychosocial factors. As such, it is a high priority to identify modifiable predictors of COVID-19 mitigation self-management behaviors of 1) adhering to physical distancing recommendations and 2) reporting COVID-19 symptoms. Through prospective, longitudinal study, this project will identify predictors of self-management behaviors and the impact on quality of life. Data will be analyzed using regression and include time-varying predictors in multi-level models.

Significance
This project includes important immediate work related to understanding the psychosocial factors that may influence key self-management behaviors and quality of life during a pandemic. Additionally, this project will enable us to better assess the very real long-term implications of physical distancing by expanding our cohort recruitment as we get ready to begin the longitudinal follow-up of this group. The long-term implications of physical distancing and other measures taken to address the COVID-19 pandemic are unknown with regard to health, well-being, and quality of life. This project has the potential to cultivate a national sample of individuals for long term follow-up which will become a key focus of our future funding applications with focus on the life-threatening and life-altering COVID-19 virus.

Appendix C
Publications of CEQL Investigators 2015 - 2020

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