The UManage Center for Building the Science of Symptom Self-Management will soon finish its second year, a period marked by continued growth in research capacity and increased interprofessional collaboration, both on campus and beyond. The Administrative Core activities have focused on evaluating the activities of the first year, enlarging our presence in the College of Nursing and on the University of Massachusetts campus, and developing relationships with industry partners.

At the beginning of the second year, several members of the UManage team attended the Annual NINR P20 and P30 Directors’ Meeting, which was focused on precision health. Later in the year, we hosted a research team from Philips Research North America to exchange ideas and explore possible collaborations. In order to expand our opportunities for collaboration, we expanded our external advisory board to include the directors of several other NINR centers.

The first-year pilot projects are winding down and the second-year projects have been started. Both second-year studies focus on improving sleep self-management, though for very different populations. The third-year pilot research projects have been selected and the principal investigators have been guided through developing complete proposals.

The Human Factors Core continues to be an inspiration for study design. Dr. Jenna Marquard has been instrumental in guiding the design of the pilot projects. As we look forward to year three, we are a fully developed center and now focus on sustainability.

Cynthia Jacelon, PhD, RN-BC, CRRN, FGSA, FAAN
UMage Center Director
The UManage Center

The UManage Center for Building the Science of Symptom Self-Management is comprised of a team of interdisciplinary scientists at the University of Massachusetts Amherst seeking to develop technologies to help people manage symptoms of chronic illness focused on fatigue and impaired sleep.

The UManage Center is funded by a five-year, $1.23 million grant awarded to the College of Nursing at UMass Amherst by the National Institute of Nursing Research (NINR). Its overall goal is to build capacity for managing symptom self-management by developing wearable, handheld, or other advanced technologies for the early self-identification, self-reporting, and self-monitoring of symptoms to decrease the functional limitations of chronic conditions, thereby improving overall wellness and reducing health-care costs. Studies will test such devices and technologies to monitor fatigue or sleep-pattern changes and help patients decide when and how to modify their activities.

To achieve this, the UManage Center is funding 10 pilot research studies over five years that offer nurse-led interdisciplinary teams the opportunity to develop strategies to help individuals improve their health, design larger, population-based studies, and expand their research capacity to work with interdisciplinary research teams.

Cynthia Jacelon of the College of Nursing is the principal investigator and director of the UManage Center. She is also the head of the Administrative Core. Her College of Nursing colleague Annette Wysocki is the director of the Pilot Project Core, and Jenna Marquard of the Department of Mechanical and Industrial Engineering heads the Human Factors Core. They are joined on the Executive Committee by sleep expert Rebecca Spencer from the Department of Psychological and Brain Sciences, big-data specialist Deepak Ganesan of the College of Information and Computer Sciences, and Peter Reinhart, director of the Institute for Applied Life Sciences (IALS). IALS plays an important role to advance interdisciplinary research to improve human health and wellbeing on this campus.
**Impacts**

The **UManage Center and Pilot Project Core** has raised the visibility of investigators in the College of Nursing across campus and among other P20 and P30 centers across the nation through oral and poster presentations. These multidisciplinary teams conduct studies that create excitement and harness new intersections between symptom self-management and the capacity of personal health-monitoring devices to improve the management of symptoms that are distressing to individuals. The impact of these studies is being extended to involve doctoral team members to ignite a new generation of investigators.

—Annette Wysocki

The **Human Factors Core** has helped ensure that all grantees account for their end users in their pilot projects. The grantee teams are now equipped with methods for understanding their users’ needs and incorporating those needs into their designs. These mindsets and skills will extend into their future interdisciplinary research projects, making them ambassadors for Human Factors across UMass and beyond.

—Jenna Marquard

The **P20** has expanded interest of our researchers in the need for symptom self-management in various populations and the development of research in this direction. Importantly, it has also solidified multidisciplinary collaborations between nurses, neuroscientists, engineers, and computer scientists. These projects represent just the start of many offshoots that we expect to develop over the upcoming years.

—Rebecca Spencer

This has been a busy year for the **UManage Center**. I believe that the College of Nursing has continued to strengthen its scholarship and contributions to nursing science. I am confident that we will continue to move from strength to strength in the coming years.

—Dean Cavanagh
The Three Cores in Year Two

The UManage Center achieves its aims through three core sections: the Administrative Core, the Human Factors Core, and the Pilot Project Core. The Administrative Core provides day-to-day management of the programs. The Pilot Project Core helps new nurse scientists develop research programs focused on symptom self-management and using wearable and handheld devices designed to support individuals with self-management of symptoms of chronic conditions. Finally, the Human Factors Core supports the pilot projects by providing both expert knowledge on the relationships between individuals, self-management strategies, wearable and handheld devices, and activities, and feedback on machine, device, and computer interfaces to improve design, use, and adaptability.

In Year Two, each core contributed to building capacity in symptom self-management science. The Administrative Core, guided by the principal investigator and the executive committee, worked to enhance the visibility of the UManage Center on the UMass Amherst campus and collaborated with the College of Nursing’s director of development to extend knowledge of the UManage Center off campus to industry and facilities serving older adults. It also expanded research capacity through educational offerings to actual and potential investigators.

The Pilot Project Core, in collaboration with the Administrative and Human Factors Cores, fostered the development of pilot project teams. Throughout the year, Dr. Annette Wysocki held regular meetings with pilot principal investigators to coach them in the implementation and administration of their research, discuss the design of presentations, possible venues for publications, and future research proposals. Through this core, the UManage Center has also offered workshops on research processes. More specifically, Dr. Wysocki guided the ongoing work of the Year One pilots, led by Dr. Rachel Walker and Dr. Karen Kalmakis, as they advanced toward completion. Dr. Walker and her team, who are investigating “Saccade parameters of persistent cancer-related fatigue: biomarker detection using computational eyeglasses,” are recruiting the final participants for the study and are moving into the data analysis, findings, and dissemination phase. Dr. Kalmakis and her team, whose study is titled “Real-time, continuous cortisol monitoring: possibilities for stress self-management,” have concluded recruitment, and are developing study conclusions and moving to dissemination and further grant submissions.

The Pilot Project Core also implemented the Year Two pilot projects. Dr. Mary Paterno is studying “Sleep self-management in pregnancy using a personalized health-monitoring device.” The other Year Two pilot is “Self-management of sleep in older adults with chronic pain.” The original principal investigator, Dr. Deborah Rosenbloom, left the university in August 2017; Dr. Raeann LeBlanc has been selected to take over. Finally, the Pilot Project Core selected the Year Three pilots and has guided the creation of proposals, mentoring the investigators in writing and submitting their grant applications.

The Human Factors Core, led by Dr. Jenna Marquard, has infused a human-factors approach into all aspects of the UManage Center and has worked with each of the pilot principal investigators to help them understand the human factors issues in their pilot projects. She has contributed to grant reviews and consultations for the Year Two and Three pilot principal investigators and is serving as a coinvestigator or consultant on each Year Two research project. In this capacity, she has met with each principal investigator periodically during the design and implementation of their research. In addition, Dr. Marquard gave a well-attended workshop on human-factors design. Her efforts have led to well-designed pilot projects that include a human-factors, participatory approach to technology design and implementation.
Year Two Activities: Industry Partnerships and Educational Opportunities

In Year Two, Dr. Jacelon presented the work of the UManage Center at several events for industry partners (see table below) and, most notably, has developed an ongoing collaboration with Philips Research North America. A visit to their labs in Boston was followed by a reciprocal visit by four representatives from Philips to the UMass Amherst campus. At this event, faculty from the UMass Amherst College of Nursing gave presentations and the Philips team were given a tour of the facilities of the Institute of Applied Life Sciences and Skinner Hall. The day concluded with a brainstorming session involving the Philips representatives and members of the UManage team. Subsequently, Dr. Jacelon has developed a National Institutes of Health R21 grant application with Philips, and one of their staff has given a remote talk to faculty from various colleges and departments at UMass Amherst.

INDUSTRY PARTNERSHIPS

<table>
<thead>
<tr>
<th>Industry Partner</th>
<th>Discussion</th>
<th>Outcome</th>
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<tbody>
<tr>
<td><strong>Johnson &amp; Johnson</strong></td>
<td>Dr. Jacelon attended a presentation from Johnson &amp; Johnson at the Institute of Applied Life Sciences regarding the companies in their portfolio and followed with individual discussions.</td>
<td>Ongoing.</td>
</tr>
<tr>
<td><strong>HD Nursing, LLC</strong></td>
<td>Dr. Jacelon discussed the relationship between sleep, fatigue, and falls.</td>
<td>Information sharing.</td>
</tr>
<tr>
<td><strong>Members of the External Advisory Board of the Institute of Applied Life Sciences</strong></td>
<td>Dr. Jacelon presented at an EAB meeting and followed up with individual discussions.</td>
<td>Ongoing.</td>
</tr>
<tr>
<td><strong>IBM</strong></td>
<td>Dr. Marquard spoke with IBM representatives about stress monitoring at the American Medical Informatics Association annual meeting.</td>
<td>They are interested in collaborating with the Year One pilot PI, Dr. Karen Kalmakis.</td>
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</table>
The UManage Center has worked to develop a regular schedule of speakers, both internal and external, to expand the knowledge and understanding of symptom self-management within the College of Nursing and across the UMass Amherst campus (see table below). Talks by our Year One pilot project principal investigators, Dr. Rachel Walker and Dr. Karen Kalmakis, have either been given or are scheduled, and we have welcomed distinguished speakers from across the country.

In October, Dr. Bruce McEwen, Alfred E. Mirsky Professor and head of the Margaret Miliken Hatch Laboratory of Neuroendocrinology at The Rockefeller University in New York, spoke to a full house of over 50 people on “The Resilient Brain: Epigenetics, Stress, and the Life Course.” He described types of stress, how the brain responds to stress, and interdisciplinary approaches minimizing the damage of stress. In November, distinguished UMass alumni Dr. Kavita Radhakrishnan of the University of Texas at Austin spoke to over 25 people about how technology can be useful in symptom self-management, how to analyze the data gathered by technology, and how to put that information to work to create healthier communities. The UManage Center is also looking forward to hosting Dr. Jeanne Alhusen of the University of Virginia in April.

### EDUCA TIONAL OPPORTUNITIES

<table>
<thead>
<tr>
<th>Presenter</th>
<th>Topic</th>
<th>Date</th>
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<tbody>
<tr>
<td>Dr. Bruce McEwen, Alfred E. Mirsky Professor, The Rockefeller University</td>
<td>“The Resilient Brain: Epigenetics, Stress, and the Life Course”</td>
<td>10/24/2017</td>
</tr>
<tr>
<td>Dr. Rachel Walker, Assistant Professor, College of Nursing, UMass Amherst</td>
<td>“Addressing Activity, Anxiety, Sleep, and Sexual Well-Being following Breast Cancer: Protocol for a Nurse-Led Biobehavioral Intervention Trial”</td>
<td>11/14/2017</td>
</tr>
<tr>
<td>Dr. Kavita Radhakrishnan, Assistant Professor, School of Nursing, University of Texas at Austin</td>
<td>“Making Sense of Self-Management Behavior Data: How Can Informatics Tools Help?”</td>
<td>11/28/2017</td>
</tr>
<tr>
<td>Dr. Karen Kalmakis, Associate Professor, College of Nursing, UMass Amherst</td>
<td>P20 Pilot Project Research</td>
<td>4/3/2018</td>
</tr>
<tr>
<td>Dr. Jeanne Alhusen, Associate Professor, Assistant Dean for Research, University of Virginia</td>
<td>“Intimate Partner Violence and Perinatal Health”</td>
<td>4/24/2018</td>
</tr>
</tbody>
</table>
The Pilot Project Process

As the UManage Center enters its third year, one of its key developments and successes has been the development and refinement of the Pilot Project process. This can be broken down into three key phases:

1) Pre-award development
2) Award supervision
3) Post-award management

The pre-award process for the Year Three pilots began in May 2017, when the UManage Center sent out a request for applications to faculty in the College of Nursing. This provided full details of the opportunity and gave clear guidelines and a timeline for submission.

This was followed by an informational session in mid-June. The deadline for letters of intent was August 1. Notifications to submit a full grant application were sent out two weeks later, with a due date of October 16. In the interim period, a mentoring process was embarked upon. Dr. Wysocki and Dr. Jacelon worked with the selected principal investigators to develop their proposals and Dr. Marquard conducted a Human Factors workshop. The applicants also met with support staff from the College of Nursing Office of Research and Business Office to prepare their budgets and budget justifications. Following submission of these full applications, the core directors conducted a mock review of each proposal and offered comments for incorporation. The UManage Center then gave notification of awards in December and has since worked with the principal investigators for their final submission to NINR.

The second part of the process is award supervision. Dr. Wysocki has met regularly with the Year Two pilot principal investigators to discuss the implementation and management of their research studies. She has provided ongoing consultation to address recruitment challenges, the engagement of community partners, and day-to-day data management and collection strategies. Similarly, as the Year One pilots have moved to the conclusion of their projects and the post-award phase, the UManage Center has looked to find ways to continue to support them. Dr. Wysocki has held check-in meetings, discussing venues for publication. In November, the three core directors conducted visioning meetings with both Dr. Walker and Dr. Kalmakis. This provided an opportunity to talk about their future plans and the process of generating further funding to advance their pilot projects.

Year One Pilot Projects

Saccade parameters of persistent cancer-related fatigue: biomarker detection using computational eyeglasses.
Principal Investigator: Rachel K. Walker

The focus of Dr. Walker’s study is the use of wearable eye-tracking technology to detect errors in saccadic parameters potentially associated with subjective reports of fatigue in breast cancer survivors. Additional funding for this study was obtained from the Rays of Hope Center for Breast Cancer Research. Dr. Walker and her team used a stratified screening process, selecting participants who fell into three groups:

(a) persons with a history of breast cancer therapy who are persistently fatigued
(b) persons with a history of breast cancer therapy who aren’t fatigued
(c) persons without a history of breast cancer therapy or other fatigue syndromes

Study visits took place at the Human Testing Center in the Life Science Laboratories building, part of UMass Amherst’s Institute for Applied Life Sciences. At each of these visits, participants were asked questions about their background, their cancer treatment, symptoms (such as fatigue), and other information that might affect their ocular motor function. They were able to skip any question they did not feel comfortable answering. After answering these questions, participants were asked to sit a certain distance from a monitor and to put on a pair of computational eyeglasses that sends information about eye movements to a nearby computer. The monitor played a 10-minute visual task involving small dots that appeared and moved around on the screen. The research team instructed participants to follow these dots with their eyes.

Data collection closed at the end of February and Dr. Walker and her team are submitting preliminary results at a symposium to be held during the annual meeting of the Gerontological Society of America in Boston in November 2018.
Real-time, continuous cortisol monitoring: possibilities for stress self-management. **Principal Investigator: Karen Kalmakis**

We were granted a one-year, no-cost extension to complete data collection, entry, analysis, and dissemination of our research. Currently, we are in the data-analysis phase of the research project.

In our polymer science laboratory, we have completed work to create a biosensor for cortisol which has resulted in a prototype, tabletop device. We have validated the accuracy of the device to detect cortisol in simulated sweat and in saliva by comparing the sensor values with traditional ELISA values. This work continues as we are now in the process of testing the reliability of the sensor to measure cortisol in human saliva by comparing cortisol values analyzed with the sensor to ELISA analysis using 20 human samples already collected.

In our human subjects lab, we have completed full laboratory testing with 69 participants, 27 with complete information needed to enter into the BRICS database. The responses to demographic and fatigue measures have been entered using the cdRNs platform. We are currently working to complete the required statistical computations for the fatigue measure prior to final submission of the data.

Once we have completed analysis, we will use this to support a future NIH grant submission. Specifically, we are interested in testing an intervention to foster resilience among young adults with histories of childhood adversity and related stress and fatigue. We plan to submit an R21 in June 2018.
Sleep self-management in pregnancy using a personalized health-monitoring device.  
Principal Investigator: Mary Paterno

This project is a clinical trial exploring use of a personalized health-monitoring device to improve sleep during pregnancy. We are using the Misfit Shine 2 to track daily sleep and physical activity among pregnant women (goal n = 24) from 24 to 36 weeks gestation. Prior to initiating the study, the study team developed and pilot-tested a brochure providing education on behavioral modifications for sleep in pregnancy, which was approved by the university’s Institutional Review Board (IRB). Pregnant women, recruited through Facebook, viewed the brochure online and answered multiple-choice, open-ended questions about the brochure. We used these data to revise the brochure.

Ethical approval for the clinical trial was also obtained from the UMass Amherst IRB. All study participants receive education on behavioral modifications to improve sleep in pregnancy, delivered by a registered nurse (RN). Participants are then randomized to the intervention or control group. Women in the intervention group are given a Misfit Shine 2; the study RN guides them in downloading the associated app to their smartphone and trains them on use of the Misfit Shine 2. In order to capture data from the device, intervention participants also download an applet called IFTTT, which downloads daily sleep and physical activity data to a spreadsheet in Google Drive. Each intervention participant is assigned a Google account specific to the study that can be accessed by the study team in order to retrieve the data.

Our research team consists of the study principal investigator, a co-investigator, a graduate research assistant who is an RN, and an undergraduate nursing honors student. We meet weekly to discuss study progress. Since launching the study, we have made adjustments to the study protocol to increase enrollment. We expanded eligibility criteria to include multiparous women and women pregnant with twins. We initially recruited participants using posted flyers, Craigslist, and two UMass Amherst online newsletters, but these techniques were deemed insufficient. We expanded our efforts to include recruitment by distributing flyers at a local OB/GYN office and through Facebook, targeting women of childbearing age within a 60-mile radius of Amherst. Thus far, Facebook has been the most successful method of recruitment. We recently received permission to recruit in-person at UMass Memorial Medical Center’s OB/GYN clinics, which is currently pending approval from the UMass Amherst IRB. To date, we have enrolled 10 women in the study and have completed the 36-week follow-up with two. We expect to close enrollment by the end of March, 2018.

Self-management of sleep using wearable sensors in older adults with chronic pain.  
Principal Investigator: Raeann LeBlanc

The long-term goal of this research is to implement self-management interventions to improve sleep quality and duration for older adults to diminish chronic pain. The specific objectives of this pilot project are to 1) determine the feasibility of using wrist actigraphy to self-monitor sleep in older individuals to help individuals identify variations in sleep patterns to improve sleep hygiene; and 2) to test whether wrist actigraphy can be used to measure differences in sleep patterns between individuals age 65 and older, with and without chronic pain. The central hypothesis is that wrist actigraphy can be used by older individuals to self-manage sleep. Wrist actigraphy will provide real-time knowledge about the biological patterns of sleep quality and duration integral to daily self-management of sleep disturbances and the associated sequelae, including pain. The proposed research will demonstrate that sleep self-management is feasible and that the benefits from the use of wrist actigraphy can be further developed as a novel intervention for enhancing sleep self-management for older adults to diminish pain.

Raeann LeBlanc, DNP, has been selected as the new principal investigator of this project. A young nurse scientist and a certified adult and older-adult community-based nurse practitioner, she is expected to complete her PhD in the next few months. Included in her team are two UMass Amherst doctoral students, one is a registered nurse from the College of Nursing and the other in the mechanical and industrial engineering department.
Looking Forward: Year Three Pilot Projects

The pilot research projects for Year Three have been selected and their principal investigators have been mentored through proposal development.

A tablet-based simple walking intervention to improve self-management of rheumatoid arthritis (RA) fatigue. Principal Investigator: Jeungok Choi

Jeungok Choi, RN, PhD, has had a long-term interest in improving self-management, particularly among older adults with low literacy skills. She also has expertise and experience in patient education using websites and mobile computers, such as tablets. The purpose of this study is to develop a tablet-based cognitive behavioral intervention application that improves self-management of fatigue among patients with rheumatoid arthritis (RA). Fatigue is highly prevalent among individuals with RA, and has a significant impact on their physical functioning and quality of life.

Studies have shown that interventions based around physical activity or exercise interventions have a moderate to significant effect on fatigue. These exercise interventions, however, are resource-intensive, requiring specially trained personnel, highly structured activities, and attendance at classes or a specified facility. Each of these components increases cost and barriers to implementation, which often leads to high dropout rates.

Self-management is a promising strategy to improve patients’ long-term engagement and adherence. This study will develop a tablet-based cognitive behavioral intervention application based around a simple walking-based physical activity with a pedometer. Such activities are easy to learn, require minimal professional guidance and equipment, and yield significant reductions in fatigue.

The project will identify any initial design issues, examine if the intervention can be seamlessly integrated into the daily lives of patients, and test the effect of the intervention on daily steps, fatigue level, self-efficacy, and quality of life with the overall aim of improving participants’ RA fatigue.

Self-monitoring of fluid status to improve sleep and reduce fatigue in patients with lung congestion secondary to circulatory overload. Principal Investigator: Elizabeth Henneman

Elizabeth Henneman, RN, PhD, CCNS, FAAN, is a nurse researcher with a focus on keeping patients safe. The long-term goal of her proposed study is to develop a home-monitoring system for patients at risk of developing fluid overload and lung congestion.

Sleep disturbances and fatigue are common in patients with circulatory overload and lung congestion. These symptoms not only impact the patient’s quality of life but are predictors of poor outcomes. It is therefore important to develop methods of identifying early circulatory overload in at-risk patients, such as those with heart failure, renal failure, and hypervolemia. The ability to identify the occurrence of early hemodynamic changes and lung congestion would allow the patient and clinician to intervene early, possibly avoiding hospitalization.

A noninvasive, hands-free system for the personalized monitoring of hemodynamic status and lung congestion that is easy to use by patients and family members in the home setting is needed. The broader goal is to create an early warning system that is feasible to design, manufacture, and test. Part of this is the development of wearable fabrics that allow for the measurement of variables related to fluid overload. The aim of this pilot is to define the end-user requirements for these wearable fabrics. The study will determine if a wearable device will be adopted and used by patients and providers. By putting human factors at the forefront, the intention is to avoid designing a system that patients and providers will not adopt or use.
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