Improving care for low-birth-weight infants

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Researchers at UC Irvine and the Charles Drew University of Medicine and Science (CDU) will monitor the day-to-day health of low-birth-weight babies and their parents as part of a comprehensive initiative designed to combat chronic illnesses associated with low-weight births.

Gillian Hayes, UCI informatics professor, and Karen Cheng, CDU psychiatry and human behavior professor, were awarded a $480,000 grant from the Robert Wood Johnson Foundation (RWJF) to explore how recorded observations of daily living (ODLs) can be used to improve clinical care for low-weight babies.

Hayes and Cheng were among five research teams in the nation selected by RWJF through its Project HealthDesign: Rethinking the Power and Potential of Personal Health Records national program to receive two-year grants that will test how health information technology can help people become more informed patients and better healthcare consumers. The grantees will work with patients to explore how day-to-day information - such as stress levels of caregivers of premature infants and medication-taking routines of seniors at risk of cognitive decline - can be collected, interpreted and acted upon by patients as well as clinicians in real-world clinical settings.

For their project, Hayes and Cheng will use mobile technology to collect and report ODLs that can enable changes in clinical practices and alert healthcare providers earlier to potential problems. The team will develop a mobile application for parents of preterm infants, called FitBaby, which builds on Hayes' past work with Dr. Dan Cooper, a UCI professor

of pediatrics. The system enables parents to easily record ODLs on smartphones, including feeding times, weight measurements, baby's activity and how parents deal with the stress of caring for an at-risk infant. The system also automatically tracks some observations through sensors in the environment.

"This work is particularly innovative in that we make it convenient for parents to record daily information about their babies by automatically sensing a number of important indicators," Hayes said. "Pediatricians will have access to the information to make earlier diagnoses, which can improve the health outcomes of babies and caregivers."

"Parent well-being is often ignored in infant care," Cheng said. "By helping parents monitor and understand the patterns of their own emotional and physical well-being, we believe that parents will be encouraged to take better care for themselves, leading to better quality of care for the babies."

Earlier Project HealthDesign work revealed that the data needed to inform day-to-day health decisions came less often from information contained in official medical records and more from information gained by monitoring health in everyday life. The new projects will build on that work.

"We know patients want better relationships with their clinicians and to make the most of their time during a doctor's visit. Through Project HealthDesign, the patients and the clinicians will be working together to collect and interpret insights from the patient's everyday life. This process will help empower people to be more informed patients and allow clinicians to determine if their care plan is working," said Stephen Downs, S.M., assistant vice president for RWJF's Health Group.

Since its launch in 2006, RWJF has committed $9.5 million in grants

and technical assistance to the program, led by a team of experts working in health information technology and patient-centered care at the University of Wisconsin-Madison. Project HealthDesign is supported by RWJF's Pioneer Portfolio, which funds innovative ideas and projects that can lead to significant breakthroughs in the future of health and health care.

In addition, the program provides legal and regulatory compliance support to grantees and contributes to the public discourse on the legal and regulatory aspects of capturing ODLs and integrating them into care processes. The program will develop resources around the cross-cutting issues regarding use and safe integrations of ODLs as well as specifically advise grantee teams on applicable law and regulations that may alter the consequences of data-sharing between patients and clinicians.

Hayes' research interests are in human-computer interaction and ubiquitous computing. She studies record-keeping technologies, particularly in natural settings, such as the home. She also focuses on the application and uses of ubiquitous computing and collaborative technologies in the areas of education and healthcare.

Cheng is a social psychologist whose research focuses on the issues affecting use of computer technology in healthcare settings. Her work evaluates the efficacy of electronic versus paper-based data collection, and the acceptance of mobile health technologies among underserved populations, locally and in developing countries.

Throughout the course of the program, all grantee teams will provide frequent updates about their work through the Project HealthDesign blog and other interactive features. To learn more, visit www.projecthealthdesign.org.