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UC San Diego researchers evaluate wearable technology privacy issues

SAN ANTONIO – Scientists at University of California, San Diego School of Medicine have completed a pilot study to examine the potential privacy and ethical issues associated with outfitting human research participants with small wearable technologies similar to smartphones or wrist-worn fitness devices.

The pilot study was conducted to provide regulatory guidance on studies that may seek to collect medically relevant behavioral information using the new technologies.

“Small, wearable technologies offer an opportunity to go beyond self-reporting about people’s health behaviors and collect more objective data,” said Dr. Camille Nebeker, an assistant professor in the Department of Family Medicine and Public Health, who is leading the MIST-E project, short for Mobile Imaging, Sensing and Tracking Ethics.

The approach raises concerns about the privacy of study participants and bystanders who may be inadvertently photographed or recorded. “The research community is grappling with how to collect data with new technologies in a manner that is responsive to federal regulations, ethically sound and socially responsible,” Nebeker said.

For the study, 211 participants wore an outward-facing automated camera on a lanyard around the neck and a GPS device and an activity monitor on a belt. The devices enabled researchers to track participants’ movements and locations and to capture images of environments in which there were most active. The participants could remove the equipment while they slept or bathed. They could also review and delete any images they did not want included in the study.

After a week of wearing the devices, 82 participants completed a questionnaire about their experiences and feelings during the study, as well as the effectiveness of privacy protection measures. The responses were analyzed to identify themes, concerns or other patterns of note.

“The take-away message of the study is that most people did not think it was a big deal to wear the devices,” she said. “The most common concern was about discomfort of wearing the devices and interference with activity.”

Participants reported little negative reaction from people they encountered during the study. “The most common reaction was curiosity about the devices and the project. The participants, generally speaking, did not encounter negative reactions from people around them,” Nebeker said. “Some bystanders, however, did express concerns that are worth noting.”

Such issues are relevant to institutional review boards (IRBs) that must formally review and approve any research project involving human subjects to ensure participants' safety and privacy.

"Our study is gathering information to guide and inform IRB decision-making," said Nebeker. "It is a first step in developing guidelines for the ethical and responsible conduct of research involving wearable devices."

Study results will be presented by Nebeker at a poster session scheduled at 6 p.m. CT on April 24 during the Society of Behavioral Medicine's 2015 Annual Meeting & Scientific Sessions in San Antonio. Nebeker is a society member.

The poster is titled: "Mobile Imaging, Sensing and Tracking Ethics (MIST-E): The Participant's Perspective." Other authors are Tiffany Lagare, Michelle Takemoto, Brittany Lewars, Elizabeth Mejia Booen and Jacqueline Kerr, all of the University of California, San Diego. The authors report no financial or other conflicts of interests.

The Society of Behavioral Medicine (SBM) is a 2,200-member organization of scientific researchers, clinicians and educators. They study interactions among behavior, biology and the environment, and translate findings into interventions that improve the health and well-being of individuals, families and communities (www.sbm.org).

The University of California, San Diego is a student-centered, research-focused, service-oriented public institution that provides opportunity for all. Recognized as one of the top 15 research universities worldwide, a culture of collaboration sparks discoveries that advance society and drive economic impact. For the fifth consecutive year, UC San Diego has been ranked first in the nation based on research, civic engagement and social mobility (<http://ucsdnews.ucsd.edu>).

This study will be presented during the SBM 2015 Annual Meeting & Scientific Sessions, held April 22-25 in San Antonio. However, it does not reflect the policies or the opinion of SBM. This poster presentation will be held on April 24. Given that this study was presented at a scientific meeting, the data and conclusions reached should be regarded as preliminary, until they are published in a peer-reviewed journal. Funding agencies played no role in this study. There are no conflicts of interest for the investigators.

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