Developing a Cyberinfrastructure for Comparative Effectiveness in Cancer Research

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Nearly four decades after President Richard Nixon declared a "War on Cancer," the disease still claims the lives of 560,000 Americans every year, despite an annual expenditure of $5 billion by the U.S. government on research to battle it.

Although much progress has been made since Nixon's call to action in 1971, cancer research is made increasingly difficult by the vast amount relevant data, which is only increasing as scientists discover new drugs and interventions and continue to evaluate their relative benefits, risks and costs.

Now researchers from the University of California, San Diego division of the California Institute for Telecommunications and Information Technology (Calit2) and the UCSD School of Medicine have been awarded $2.6 million over two years from the U.S. National Institutes of Health's National Cancer Institute (NCI) to prototype a cyberinfrastructure that would allow scientists to collect and interpret data from a variety of sources to compare the effectiveness of preventative measures, drugs, treatments and interventions.

The Cyberinfrastructure for Comparative Effectiveness Research (CYCORE) project for cancer research will be scalable, open-source and user-friendly. CYCORE will aggregate data from clinical trials, patient medical records, self-reported and objectively monitored social and behavioral data, data on cancer outcomes from regional cancer registries, and cost-benefit analyses.

"A unique aspect of CYCORE will be its focus on expanding the quality and types of data that can be incorporated into cancer comparative effectiveness studies," said Kevin Patrick, MD, a professor in UC San Diego's Department of Family and Preventive Medicine and the principal investigator for the Calit2 component of the project. "From the outset, a primary focus will be on tackling the problem of obtaining, in patients' homes, objective person-level data on behaviors such as adherence to cancer medications, diet, physical activity, sleep, environmental exposures and quality of life."

"These factors are enormously important in the course of medical treatment, but are almost always assessed through infrequent and after the fact self-reports," he added. "To have these data in near-continuous form will greatly expand our understanding of who does well on what treatment, when, why and for how long."

The Calit2 researchers are partnering with The University of Texas M. D. Anderson Cancer Center - the nation's foremost institute for clinical cancer care - on the $3.86 million Grand Opportunity grant. The multidisciplinary consortium of investigators will first determine the parameters of the project and then create the prototype cyberinfrastructure for data aggregation, integration, processing, mining, storage and retrieval.

Once the data acquisition systems and software have been developed, the M. D. Anderson team will beta-test the prototype in clinical trials. Another thrust of the project will be to develop related applications for the cyberinfrastructure, including a Web-based user interface, home and mobile phone-based sensing devices to gather real-time patient data, and the use of novel brain-based device methods for data analysis.

"CYCORE could be used across the whole spectrum of oncology research," says Wendy Demark-Wahnefried, a professor of behavioral science at The University of Texas and a co-principal investigator on the project. "It will allow us an opportunity to study various factors that heretofore we have not been able to study, such as the role that diet plays, or supplements, or secondhand smoke. It's hard to capture those data and that's why we need the expertise of the researchers at Calit2. As the CYCORE system expands in size and scope, the oncology community could upload the data from a vast number of clinical trials. By having more data points we'll be able to better create models for prevention, treatment and recovery."

"UC San Diego has a unique combination of talent in the areas of biomedical and behavioral science, engineering, computer science, and informatics," explained Lucila Ohno-Machado, MD, PhD, Chief of the Division of Biomedical Informatics and professor in UCSD's Department of Medicine. "This combination enables the implementation of transformative projects such as CYCORE. A robust infrastructure for data sharing in biomedical research is long overdue, and CYCORE will be filling an important role in comparative effectiveness research, which is critical for the development of a sustainable healthcare model. Focusing on cancer is a great choice, as it is a data-rich domain for which some building blocks for efficient data integration and data analyses already exist."

The CYCORE project will benefit from the unique visualization technologies based at Calit2, including the virtual-reality StarCAVE, where researchers wearing stereoscopic glasses can 'walk into' digitally rendered models of hyper-magnified biological structures. Calit2's HIPerSpace tiled-display wall - which features nearly 287 million pixels of screen resolution - makes it possible for researchers to look at large datasets on a massive scale, while tele-collaborating with other institutions in real time.

The mobile technologies and wearable sensors that eventually will be incorporated into the cyberinfrastructure will also come from the Center for Wireless and Population Health Systems (CWPHS), a 'clinical outpost' of the UCSD School of Medicine at Calit2. CWPHS is led by Patrick, who is also a member of UCSD's Institute for Engineering in Medicine.

The CYCORE cyberinfrastructure will represent a significant advance in data aggregation and computer networking, according to Calit2 Chief System Architect Ingolf Krueger. "This cyberinfrastructure is uniquely positioned in its responsiveness to stakeholder needs," explained Krueger. "It is policy-reactive, meaning that it's a system that will change its behavior in response to direction by the researchers and other stakeholders themselves, and not just outside software developers. This saves time and enables more agile collaboration by cancer researchers who are searching for a cure."

"I consider CYCORE as a triple-play win for UC San Diego and Calit2," claimed Patrick. "It will further strengthen what we are doing to develop cyberinfrastructure for health-related research, in particular research that capitalizes on the increasing availability of wireless and mobile technologies and wearable sensors. Our work in this area related to measurement of health behaviors is highly novel and this is one reason that M. D. Anderson approached us to participate in this project. Once the CYCORE prototype is developed and tested, our plans include using it in other settings, including in our own cancer-related research here at UC San Diego." Patrick is a member of the Moores Cancer Center and has been principal investigator on several NCI-funded projects.

The UCSD researcher also notes that comparative effectiveness research is a cornerstone of the Obama Administration's aims for health-care reform. "It's critical to develop a health information infrastructure that can be used by comparative effectiveness researchers," noted Patrick, "and CYCORE will help set some of the foundational aspects of this."

The NIH grant is one of the largest received by UC San Diego under the 2009 American Recovery and Reinvestment Act (ARRA) federal stimulus funding program: "This project will bring new individuals into the workforce in San Diego, including at least three high-level software programmers, and also support several doctoral-level students and post-docs - an important benefit in this time of rising fees for UCSD students," Patrick said.

Added UCSD Vice Chancellor for Research Arthur B. Ellis: "UC San Diego is delighted to be part of this CYCORE project that exemplifies ARRA goals. Not only will the CYCORE project support a large cadre of interdisciplinary researchers, but the cyberinfrastructure to be developed will spawn a variety of new capabilities and technologies that will help combat cancer and more generally contribute to the health of our society."

Experts predict that U.S. spending on health care will double to more than $4 trillion annually by the middle of the next decade - a trend that Ramesh Rao, Calit2's UCSD division director, argues is not sustainable.

"We need to advance the science of more rapidly understanding which therapeutic approaches for cancer - and indeed for all areas of health - are working, and which aren't," concluded Rao. "We think a big part of what will enable this will be through harnessing the capabilities of the kinds of information technologies we have at Calit2 and UC San Diego."

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