

Apple's Research Kit Development Framework for iPhone Apps Enables Innovative Approaches to Medical Research Data Collection

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Editorial

In March 2015, Apple announced a new iPhone application development framework for medical research called Research Kit [1]. Research Kit makes it easy for investigators and software developers to build applications for collecting medical research data. No doubt investigators are excited by the potential for Research Kit. Hundreds of millions of people have iPhones, and may now contribute their iPhone data to medical research on a scale that has not been available before.

The Research Kit framework provides 3 customizable modules that address common elements of medical research studies: informed consent forms, surveys, and real-time active tasks (e.g., gait and tapping motor activities, 6-minute walk tests of fitness, spatial memory tests of cognition, and phonation voice tests) [2]. Modules take advantage of iPhone sensors and capabilities for tracking movement, taking measurements, and recording data. New modules may also be developed and integrated with iPhone's health and fitness data collection capabilities (e.g., daily step counts, calorie use, sleep-wake cycles, nutrition, and heart rates).

Prior to the announcement of Research Kit, Apple worked with five institutions to develop five example Research Kit apps made available upon announcement. These apps were developed to study cardiovascular disease, Parkinson's disease, diabetes, breast cancer, and asthma. Many more apps will follow after the April 2015 Research Kit framework launch for investigators and developers worldwide. This launch is an opportunity for investigators to use the large iPhone user and developer communities as partners in medical research. It will enable innovative approaches to data collection that have the potential to streamline current operational inefficiencies in medical research. And it could improve data accuracy, granularity, and our understanding of the social, environmental, and behavioral determinants of health [3].

Apps developed with Research Kit have the potential to streamline current medical research operational inefficiencies in study recruitment, data collection, survey administration and participant retention. Research Kit may allow study recruitment effort to be outsourced to users because anyone with Research Kit, no matter where they are in the world, may browse for the Research Kit studies they want to screen for and join. The need to schedule in-person visits for data collection and manual administration of paper surveys is not necessary with Research Kit, as data collection and surveys are done on iPhones. Users also control what health information they provide to each study and can see the data they're sharing, so privacy level and data sharing are user-maintained, with responsibilities for ensuring research regulation compliance maintained by investigators [2]. Additionally, users may track their own data and potentially discover correlations between their symptoms and daily actions, which may

improve retention by providing more participant engagement and investment in the research.

Apps developed with Research Kit also have the potential to increase data accuracy and granularity through larger study populations and real-time data collection. The hundreds of millions of iPhone users worldwide may provide a large and diverse study population that more accurately represents real populations and provides increased statistical power for analyses [2]. Additionally, real-time data collected wherever participants are as they go about their lives may provide more complete health information and may supplement data collected during hospital or clinical visits to provide a more complete picture.

Real-time data collection has the potential to improve our understanding of the social context, environmental influences, and personal behavior determinants of health [4]. Real-time data on social activity (e.g., who you call, text, and interact with) could improve our understanding of how social context influences health, such as with influenza and Ebola. Real-time data collected on environment (e.g., location, altitude, temperature, air quality) could improve our understanding of the environmental contribution to health, such as with asthma and heat stroke. Similarly, real-time data on activity (e.g., cycling, walking, and running), daily steps, nutrition, sleep/wake cycles, heart rate, mood, medication adherence, and survey data could improve our understanding of the behavioral determinants of health, such as with depression and eating disorders.

Research Kits Potential is not without its Challenges

One challenge is knowing when and how to use the iPhone users and developer communities to appropriately address medical research problems [3]. Given the voluminous data that may be collected, it may become increasingly valuable to forecast whether or not collected data would be more costly to manage and analyze than its value [5]. Similarly, problems associated with eligibility verification, data quality, and data security must be identified and addressed early. Apps must be developed to high security standards to ensure secure transfer, storage, and if necessary, de-identification of personal health information for regulatory compliance. Demand for research participants may eventually drive developers to improve data security standards.

Another challenge is with operationalizing the development of these apps in-house within medical research settings [6]. Proven innovation methods from other fields are only beginning to be adapted to the medical field [7-9] and big data solutions for medical research like Research Kit are not yet connected to medical care. The current ways of practicing and organizing medical care are deeply entrenched and principles guiding high-impact innovation are evolving faster outside health care than inside [5,6]. Innovations like Research Kit could

transform medical care, but the medical industry must undergo fundamental changes before stakeholders can capture its full value [10].

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