Collecting patient-reported outcomes via smartphones

C Tracker for the Swiss Hepatitis C Cohort

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Background and introduction

The introduction last year of ResearchKit, an open source toolkit for iOS facilitating the creation of smartphone research apps, has sparked renewed interest in smartphone-driven biomedical research. In addition to the initial five research apps, about a dozen more ResearchKit-powered apps are now available to iOS-using participants in the United States. In April 2016, ResearchStack – the Android counterpart to ResearchKit – was released, enabling researchers to finally include participants using the most popular mobile operating system. The field now has powerful informatics tools at its disposal, but it still needs to prove that the approach to collecting patient data for biomedical research via smartphones is useful and sustainable.

Methods

The C Tracker study is an apps-based trial, assessing activity levels over time of patients with hepatitis C. The app distributes surveys to study participants on a 2-weekly basis and returns activity data, such as steps taken and time spent exercising, along with survey answers. Users are identified by a random number, all data is de-identified and encrypted before being sent over the Internet. The well-known i2b2 research backend serves as data storage. To provide value to participants, the app also contains a dashboard showing their recent activity, sources of information about hepatitis C and its treatment, and other tidbits, such as a map of the US showing participant origin.

We are bringing C Tracker to Switzerland, extending its target population from anonymous “in the wild” recruitment to patients already enrolled in the Swiss Hepatitis C Cohort Study (SCCS). The data delivery toolchain, available open-source under the name “C3-PRO” and using the upcoming Fast Healthcare Interoperability Resources (FHIR) standard, is extended with a separate backend system storing participant identity data, linking the app’s user identifier to participants’ SCCS study identifier. Circumnavigating the cloudy waters of electronic consent in Switzerland, we are collecting paper-based consent from participants during their annual clinic visit, at least initially. We are also adapting our toolchain to ResearchStack and hope to port the complete app to Android in a timely manner.

Results and discussion

At this early stage in the project, we have identified steps in the original approach in need of adaptation to Switzerland. Most importantly, we have built an “identity manager”, allowing us to collect paper-based consent from patients, record the consent electronically and provide participants with a link to “unlock” the app, allowing access to the research study part of the app as a fully consented user. Although this adds another system that research coordinators need to use, its use is straightforward, only requiring entry of five data items. The link to the app can either be established immediately via QR code or by emailing a link to the participant that will open the app.

We are in the process of finalising the server components and the app and hope to enrol our first participants in the near future. All our tools will be made available open-source.

Disclosure statement

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