mQoL: Mobile Quality of Life Lab: From Behavior Change to QoL

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Abstract
Nowadays, the app stores host a variety of mobile health solutions. Smartphone users can choose from tens of thousands of applications, designed to prevent or manage certain diseases, or induce behavior change to improve health and life quality in general. However, the value of most applications remains unclear, as they stop short from documenting adherence to medical evidence. We review the fundamental mobile health challenges and propose Mobile Quality of Life Lab (mQoL), a mobile health platform which addresses the identified challenges and leverages recent developments to facilitate the deployment of much-needed longitudinal, multidimensional, evidence-based studies that are minimally obtrusive for the participants, yet provide high value in terms of the collected datasets, as well as potential for behavior change towards improving Quality of Life.

Author Keywords
Mobile Application; Longitudinal Data; Behavioral Marker; Self-Assessment; Quality of Life

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H.4.m [Information systems applications]: Miscellaneous

Introduction
There is a growing need for transdisciplinary efforts towards understanding fundamental theories of Quality of Life (*QoL*)

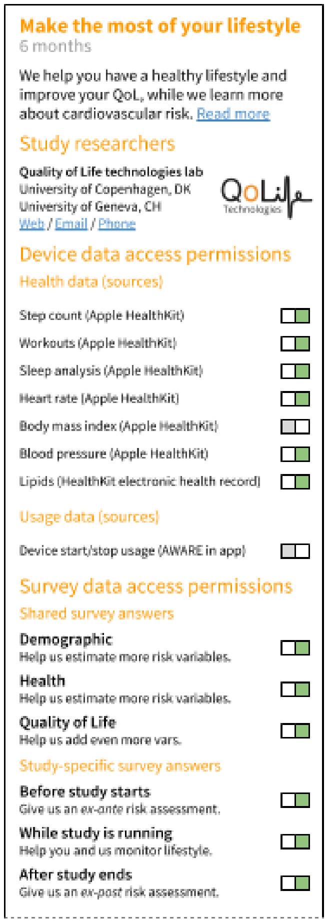

Figure 1: mQoL study standard format: title, duration, description, researchers, data permission requests: device-reported (health and usage) and self-reported (shared and study-specific).

and linking these to an understanding of complex practical problems related to assessing day-to-day individual's QoL [11]. According to the World Health Organization (WHO), the QoL is *"individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns"* [4]. The QoL state is mainly influenced by (un)healthy lifestyle over long periods (*longitudinal*) and multiple dimensions (*multidimensional*) of behavior.

In parallel, personal, miniaturized devices have programmable sensors which are becoming more accurate as technology progresses [3] and collect multiple dimensions of data simultaneously, continuously, in time, and in context. Enabled by them, mobile health (*mHealth*) apps have become the artifact of choice for many recent exploratory and behavior analytics and change studies, conducted by researchers and companies alike. Within mHealth, participants engage in data collection and interventions through numerous channels (e.g., text, audio, graphics, video [14]) and generate device-collected behavioral *markers* and self-reports.

Interested individuals look for mHealth apps in the same stores as any other apps [14], but as of today, there are over 43 thousand mHealth apps [10]. Ideally, the apps would enable effective behavior change towards QoL improvement in the long-term. However, the actual value added by most is unclear due to a lack of medical evidence. Additionally, for researchers, mHealth studies are challenging to conduct, as there is no open, versatile platform enabling the deployment of longitudinal, multidimensional, and evidence-based studies.

mHealth challenges

SCIENTIFIC RIGOR: Poor scientific rigor characterizes most mHealth apps. They do not identify, apply, or document behavior change theories and techniques [8]. Their studies lack bias assessment in participant groups [1], miss control groups [17], or contaminate them with (access to) interventions [1]. They make recommendations without following evidence-based medical guidelines and best practices [9] and are not anchored in a real-life context. Regulation was attempted by international bodies (FDA in the US, TGA in Australia, MDD in Europe) and research initiatives [10], but no definitive standard emerged, putting a burden of choosing useful and harmless mHealth apps on the user.

HOLISTIC ASSESSMENT: In general, apps considering individual participant characteristics, such as wellbeing, lifestyle, personality, and changing needs, can facilitate a holistic view [14], improve the effectiveness of interventions [12], and keep participants engaged longer. Many apps, usually commercial, focus on overall lifestyle, health, and wellbeing, but with unclear effects of behavior change interventions. Other research apps contain healthy behavior change interventions, e.g., combatting sedentarism or quitting smoking, yet they focus only on preventing or managing specific diseases, e.g., diabetes or dementia.

DATA DIMENSIONALITY: For behavior change, feedback based on multidimensional data (e.g., physical and psychological state) yields stronger motivation and avoids reporting flaws [16]. In some studies, multidimensional data is necessary. However, few studies address multiple dimensions [5] and few datasets integrate device data with other data types [6], e.g., blood tests, not only because obtaining the latter is difficult, but also because many researchers choose self-reports instead of reliable data sources [9].

DATA TIMESPAN: mHealth enables the gathering of longitudinal data, allowing the observation of short, medium, and long-term effects. However, many studies continue to focus on short-term data acquisition [5] and involve small samples of participants, ranging in the tens. Additionally, only a few apps (e.g., [15]) are kept novel for prolonged periods, leading to diminishing effects, interruptions in data collection, and attrition [1]. If larger samples were recruited, then studies would continue to report small improvements, but impactful over the whole population [5].

DATA CONTROL: mHealth apps provide the opportunity for researchers to access and create massive datasets [9]. Apps need to manage these datasets securely and provide complete and accurate information about data generation, measurement, collection, retrieval, and analysis. However, many apps even lack an adequate privacy policy [10].

MHEALTH BURDEN: Researchers are forced to treat the mHealth app as only one aspect of the study, making it difficult to satisfy modern participant expectations regarding maintenance, support, and updates [1, 5, 9] or implement behavior change features (e.g., personalized messages, reminders, or dashboards [13]). Instead, the harsh reality is that researchers often need to keep the app alive in between rounds of funding.

To our knowledge, there is no holistic mobile app for researchers and smartphone users to deploy and participate in evidence-based longitudinal, multidimensional studies to change behaviors and improve QoL in the long-term.

Figure 2: mQoL study standard format (continued): scientific evidence (behavior change and medical), participation consent, and participant signature.

mQoL solution

Faced with these challenges ourselves and aiming at holistic QoL assessment based on behavior change interventions in our QoL technologies lab, we are researching a *Mobile Quality of Life Lab* platform, denoted *mQoL* and operationalized via a mHealth app in Apple iOS, bringing the following benefits for researchers and participants.

RESEARCHERS can now only focus on designing the studies. They can obtain rich behavioral datasets by retrieving longitudinal, multidimensional behavioral markers in time and context, as well as self-reported demographic, medical, and QoL information from participants, all consented, pseudonymized, and structured. The platform is designed to accommodate only exploratory and interventional studies grounded in medical evidence. Its components are designed to maximize participant retention while minimizing study participation burden.

PARTICIPANTS can make sense of behavior and life quality and potentially change behaviors in the long-term, by using only evidence-based studies. While participating, they receive personalized, timely, and contextual information from studies, helping them monitor, observe, and reflect upon daily life and its long-term health and QoL consequences.

mQoL architectural choices

STUDIES: The central concept of mQoL is the *study*, that acts as a research template. Within a study, researchers specify motivations and expectations, provide scientific evidence, plan interventions, specify the needed types of device-reported data, and schedule the retrieval of self-reported data. All studies follow a standard format. Figures 1 and 2 depict a study in this format, on behavior change for reducing cardiovascular disease risk, a current topic in our research. mQoL also allows parallel tracks within the same study, enabling, e.g., both control and intervention groups to participate. We call studies that do not require active participation, e.g., self-reports, *silent*. To avoid contamination of control and intervention groups, mQoL allows at most one non-silent study participation at a time.

DEVICE-REPORTED DATA: mQoL uses device-reported individual health data and smartphone usage data. Health-related data is generated, measured, and collected on the

mQoL surveys

QoL survey: provides a basic, yet holistic view of the participant's QoL. It is based on, e.g., the WHOQOL-BREF [4] validated scale and ideally collected every two weeks.

Demographic survey: helps researchers recruit samples of interest for studies. It contains questions about, e.g., the age, gender, and country, and it is collected rarely.

Medical survey: helps researchers recruit samples of interest, personalize health-related behavior change interventions, and avoid silly recommendations. It includes questions about medication, participant diseases, and family history, and it is collected infrequently.

Personal survey: allows participants to provide contact information, e.g., email or phone, to receive updates about new studies on those channels.

device, continuously, unobtrusively, and independently of the app. All such data can then be retrieved by each study upon consent. Additionally, mQoL allows researchers to design custom tasks in studies, e.g., asking the participant to perform a short-term activity such as a six-minute walk test, from which device-reported data is collected.

SELF-REPORTED DATA: mQoL allows studies to design and schedule self-reported surveys and request access to any of the following self-reported surveys, *shared* between studies: a *Quality of Life* survey, a *demographic* survey, and a *health* survey. An additional *personal* self-reported survey is only visible to mQoL providers. For details, see the **mQoL surveys** side note.

MODULES: mQoL for participants is organized in five tabs, each tab having its modules (Figure 3). (1) The *Data* tab contains modules for managing retrieved data: which studies retrieve which data, and options to pause, restore, stop, and delete each type of data within each study. (2) The *Explore* tab contains two lists with the active and available studies. From this tab, participants can see information (e.g., dashboards) in active studies and can signup for an available study. When the number of studies increases in our app, we plan to design an onboarding feature to help participants choose those that suit their interests and can benefit them most. (3) The *Account* tab contains modules for managing the token and for answering all shared self-reported surveys. (4) The *Settings* tab contains the privacy policy, terms and conditions, and other minor functionalities, e.g., notification management. (5) The *Control* tab is the main entry point in the app. It contains transient, inversely chronological *cards*, which provide information or require action inside modules of the other tabs. Some cards can be announced by notifications with reminders and personalized messages. See a clickable mock-up at http://bit.ly/mobileQoLlab.

TECHNOLOGIES: mQoL leverages the Apple iOS platform, for several reasons. First, the App Store has a stricter review process than other platforms, yielding to more qualitative apps. Then, iOS allows device-reported and self-reported data collection via often-used and well-documented frameworks, making study design and participation experience familiar. Last, Apple continues to invest in digital health at scale (e.g., they released an API for electronic health records in June 2018). For details, see the **mQoL technologies** side note.

mHealth challenges vs. mQoL

SCIENTIFIC RIGOR: By reviewing the mandatory scientific sources included in the studies and their implementation, including requiring an external review, e.g., an ethical approval, mQoL ensures all studies rely on the latest medical evidence. While this model is strict and laborious, it helps mQoL become the authoritative app for scientific studies researchers and participants ultimately need.

PARTICIPANT ASSESSMENT; DATA DIMENSIONALITY AND TIMESPAN: mQoL addresses these challenges through the retrieval of continuous device-reported and scheduled device- and self-reported data, performed in parallel and over long periods as part of studies.

DATA CONTROL: For pseudonymous data retrieval, upon installing mQoL, the participant sets up a *token*. This token (and no other personal information) will identify the data retrieved from the participant. Such an approach has been used in recent health studies [7]. For retrieving data, each study requests only the most granular data types it needs, e.g., physical activity $\rightarrow$ walking $\rightarrow$ steps $\rightarrow$ daily count. However, for studies which need to transfer data out of the device, the app securely transmits data upon separate con-

mQoL technologies

Apple HealthKit: framework used to collect and retrieve individual health data, including electronic health records (since June 2018). https://developer.apple.com/healthkit/

AWARE: framework used to collect and retrieve smartphone usage data. http://www.awareframework.com/

Apple ResearchKit: framework used to design consents, surveys, and tasks for the participant. https://developer.apple.com/researchkit/

Charts: library used to draw interactive dashboards. https://github.com/danielgindi/Charts

Open mHealth: schemas used as a format for health data exported outside of the device. http://www.openmhealth.org/

Parse: library used to export data to the mQoL Smart Lab [2], which uses this technology. https://docs.parseplatform.org/ios/guide/

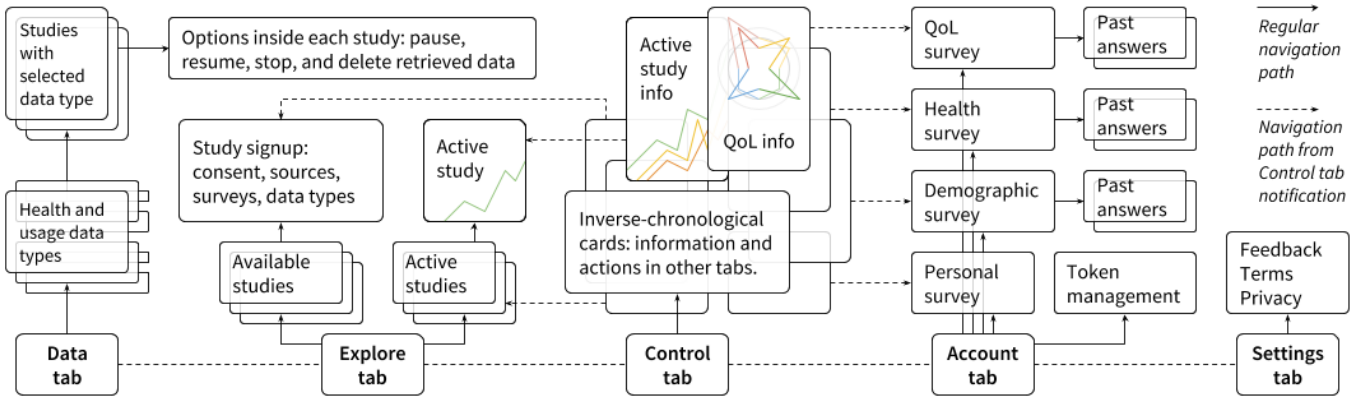

Figure 3: Conceptual architecture of *mQoL*: tabs and modules.

sent. To retrieve or export data, mQoL needs to send the participant a notification, which implies a permission request for every processing.

MHEALTH BURDEN: mQoL simplifies study deployment for researchers, by providing a platform that provides a format for designing studies as well as well-documented and often-used frameworks and libraries for consents, tasks, health data, usage data, and survey data, helping them worry less about app maintenance or study survival.

Conclusion and further work

We reviewed the benefits, needs, and shortcomings of the mHealth domain and observed that there is no holistic platform for researchers and smartphone users that allows them to conduct and participate in evidence-based longitudinal, multidimensional studies. We propose *mQoL*, a mobile platform designed to addresses this gap as well as the ardent needs of mHealth in general, with the potential of being leveraged in numerous evidence-based studies, to change behaviors and improve QoL. The research is ongoing, and at the moment we are looking into ways of streamlining the study designs for researchers, as well as putting in place mechanisms to evaluate evidence basis for studies. However, it is real-world studies that can ultimately validate mQoL. The first study is our project on behavior change for reducing cardiovascular disease risk, to be deployed later this year. Medical experts engaged in the project will provide feedback on the mQoL platform and study designs.

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