Development of a smartphone app for adolescents with lupus: a collaborative meeting-based methodology inclusive of a wide range of stakeholders

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Abstract

Traditional challenges of creating a medical app include hearing the voices of various stakeholders as a collective rather than in a consultative process that is sequential. This report describes the development of a mobile (smartphone) app for adolescents with lupus as well as the process that was used to overcome the challenge described above. The development of the smartphone app addressed optimal ways to incorporate information about 1) lupus, including the effects of both the disease and the medications used to treat it; 2) how life choices can affect lupus patients' condition; and 3) ways to increase self-management and communication. The collaborative concept-generating and requirements-gathering methodology was used during a two-day workshop with a range of stakeholders (ages 16–59 years) that focused on leveraging user-centered design methods to generate guidance to mobile app developers. The app development process conducted during the workshop included the following steps: 1) recruiting a goal-focused collaborative group, 2) defining app objectives, 3) evaluating potential needs of users, 4) brainstorming app features and use-case modeling, 5) reviewing existing app features and prototypes, 6) refining functionalities, 7) writing user narratives, 8) visualizing navigation and feature design, and 9) identifying content. The use of creative devices such as drawing interfaces fostered fun, engagement, and sustained energy, and the use of a brainstorming technique leveraged methods that ensured an inclusive process so that even participants who were shy, quiet, or easily intimidated by "professionals" felt confident to contribute. In addition to a name change for the app, project outcomes included the selection of the following app features: symptom tracking; appointment and medication reminders; a social media component; a medical summary; easy navigation; informational content; gamification; and personalization (options for customization).

Keywords

Adolescent; lupus erythematosus, systemic; information technology; informatics.

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The development of native apps for smartphones and the emergence of optimized mobile websites present an important means through which patients with chronic conditions can become informed about their illness, supported in their treatment plans, and connected with others. Smartphone and tablet adoption is increasing, with recent data indicating 37% of teens in the United States have a smartphone, and 50% of them access the Internet primarily through that device (1). These trends are comparable with those found across other countries in the Americas. Based on current adoption trends, it is estimated that by the year 2020 there will be 10 billion mobile Internet devices in use worldwide—five times the current estimate of 2 billion smartphones and tablets in use today (2).

Despite this growing trend, most intervention programs for transition health (adaptation to adult care and self-management from pediatric, child-oriented care) are delivered in person or through print materials, with only occasional use of websites (3). When health care information is presented through technology, it is typically used to track and/or transmit data. Few technologies feature interactive prompts, social networking, or tools for building self-care skills (4). Research has shown that young people do not change their behavior just by receiving information (5–7), so information is likely to be helpful only when linked to advice and motivation for clinical management (8).

A smooth transition from pediatric to adult care is critical to the health and well-being of adolescents with chronic conditions such as systemic lupus erythematosus (“lupus”). Teens with lupus need reliable information about their disease, knowledge about the effects of both lupus and lupus medications on their lives, and an understanding of how life choices affect their condition (9). Strong self-management and communication skills are also recommended to enable them to manage their illness autonomously (10). Without sufficient preparation, patients have nonoptimal adherence to proposed treatment plans, deficiencies in knowledge about their condition, limited self-care skills, and decreased follow-up visits after transfer to adult clinics (10–12). Studies show that there are more negative than positive outcomes when youth with special health care needs become adults, so innovative and effective approaches to help them adapt to the transition to adulthood are essential (10, 11, 13, 14).

**LUPUS SMARTPHONE APP**

Given the authors’ experience that adolescents with lupus make use of smartphones and associated technologies, it was felt that circumstances were optimal to develop an app in collaboration with youth living with lupus, as well as other stakeholders. This report describes the collaborative concept-generating and requirements-gathering methodology used with a range of stakeholders during a two-day workshop that focused on leveraging user-centered design methods to generate guidance to developers of a mobile app for adolescents with lupus. The methodology was based on the assumption that all workshop participants were worthy of respect and had important contributions to make and thus included the use of short, varied exercises to hold the attention of all members of the group and allow those with different styles of learning/sharing an opportunity to contribute. Another assumption of the methodology was the idea that an enjoyable process would produce better results and that successful, respectful interactions could take place among workshop participants with a broad range in age (16–59 years), technical expertise, experience, and knowledge of lupus. As iOS was the dominant operating system at the time, and financial limitations precluded the development of multiple versions of the app for different platforms, the app was designed for Apple devices only, although other versions (e.g., Android) are planned for future development.

**Development process**

The app development process included the following steps: 1) recruiting a goal-focused collaborative group, 2) defining app objectives, 3) evaluating potential needs of users, 4) brainstorming app features and use-case modeling, 5) reviewing existing app features and prototypes, 6) refining functionalities, 7) writing user narratives, 8) visualizing navigation and feature design, and 9) identifying content.

**Recruiting the collaborative group.** An interdisciplinary collaborative group composed of health care professionals (in rheumatology, transition and adolescent medicine, and psychology), collaborator youth living with lupus (who were paid a US $100 honorarium), one adult with childhood-onset lupus, and specialists in mobile technology (architects and developers) was recruited to participate in the workshop. The app development process conducted through the workshop was led by one of the coauthors (TK), an expert in the field of health care digital/mobile marketing strategy.

Prior to attending the workshop participants were given “homework” assignments, including: 1) reading a brief primer on navigation options for mobile applications and the mobile Web (Figure 1, provided as Supplementary material), designed to familiarize members with trends in mobile app architecture and encourage reflection about the user experience; and 2) completing a guided exercise that included finding an eHealth application, reviewing it, and filling out an “App Profile” containing the name of the app and where it could be found online (the Web address), a brief summary of the app, a description of its notable features and strengths/weaknesses, and observations about the app visuals and user experience. This exercise helped participants gain an understanding of both the eHealth application landscape and best practices in user experience/functionalities.

The collaborative group met at The Hospital for Sick Children in Toronto, Ontario, Canada, for a 1.5-day workshop series. Twenty-three invitees intended to come to the meeting, but due to illness, only 18 participated in the workshop. All stakeholder groups were represented among the workshop participants, and ample time was allowed for this diverse group to interact informally.

**Defining app objectives.** The main objectives of the app (educating adolescents with lupus about their condition and helping them make a successful transition from pediatric to adult care; assisting them with medication management and promoting...
their autonomy; enabling symptom tracking; and facilitating communication with care providers and other teens with lupus) were presented to workshop participants, and issues related to health transition and the challenges associated with chronic disease management were discussed. Background information on lupus (associated symptoms, treatment side effects, and socio-emotional factors) was also provided, followed by a group discussion of the app objectives.

Evaluating potential needs of app users.
To help all participants gain a more comprehensive understanding of the end-user, one participant shared her experiences as both an adolescent and young adult with lupus. Key differences between pediatric and adult care cultures were identified. This speaker also outlined several strategies for coping with a chronic condition. Input was also received from adolescent participants with lupus.

During the presentation by the adult lupus patient, each participant was asked to 1) take notes on the aspects of the patient experience that were described and 2) classify them into eight categories: 1) physical, 2) emotional, 3) intellectual (knowledge-seeking), 4) social, 5) practical, 6) technical, 7) system (health care team, community supports, etc.), and 8) miscellaneous (personalization). These categories were selected as reasonable means of dividing and organizing information and services suitable for an effective digital health care intervention aimed at patient education and support.

Brainstorming app features and use-case modeling.
Participants were divided into small groups that typically included individuals with different experiences, ages, and professional roles. Each group was asked to contribute to brainstorming potential app features classified by the eight pre-identified categories. Brainstorming sheets were posted on the walls of the workshop space, and the small groups of participants circulated past them in sequence in a series of short time intervals. During each interval, each group reviewed, modified, and contributed additional concepts to the brainstorming sheets.

Following this exercise, participants were assigned to groups of two, and each pair was given a category on which to focus along with the output sheet for that category from the brainstorming session.

Each pair of participants selected what they considered the most essential feature idea brainstormed in their category and conducted an exercise aimed at defining software features, customized for adolescents living with lupus and based on the concept of “use-case modeling.”

A use case is a list of steps that define interactions between an “actor” and a system. For the lupus smartphone app, use-case modeling for each app feature and user included the following six steps:

1. Identifying the actor (the user of the feature), pinpointing the feature objectives, and visualizing the step-by-step process involved in its use
2. Determining potential obstacles and possible resolutions or alternatives
3. Defining the feature benefits
4. Identifying underlying assumptions and biases
5. Defining the criteria for evaluating the feature’s success
6. Determining the implications of the feature for other types of users.

Upon completion of their use-case analysis, based on the steps above, each pair of participants was assigned to a different category/feature idea to further refine it using the same process.

Reviewing existing app features and prototypes.
A roundtable discussion was conducted in which participants shared the app review (“App Profile”) they had completed for their homework assignment in preparation for the workshop. Strengths and weaknesses in the scope, interface, and design of various health apps were considered. Two lupus app prototypes developed as part of a competition for software and health care students (“Apps for Health”) were also evaluated.

Refining app functionalities.
Each pair of participants presented one feature idea and the corresponding use-case model analysis to the group. Input on and/or concerns about the app features were solicited from participants. Following a group discussion, a vote was taken for each feature in which participants were asked to select the degree of essentialness of each feature (“must have,” “should have,” or “could have”) to prioritize the desired features of the app democratically.

Writing user narratives. In pairs or small groups, participants drafted brief user narratives for selected feature ideas. The user narratives indicated the actor (e.g., a teen with lupus), their objective (e.g., “track a new symptom”), and a summary of the interaction with the device. In some cases, participants envisioned what might occur if the initial objective was not achieved, and how the user might seek to correct it.

Visualizing app navigation and feature design.
Paper templates of a blank iPhone screen were distributed to the participants, who were divided into small groups. Each group selected a feature idea and sketched provisional interface designs using pencils, pens, and markers. Participants were asked to envision menu and navigation options, as well as the physical layout of features. The sketches were then posted on the wall and reviewed by all workshop participants, who evaluated and commented upon the different interface design ideas (Figures 2–4, provided as Supplementary material).

Identifying content.
Workshop participants generated informational content on a series of pre-identified topics including: 1) disease information, 2) health systems/clinics/providers, 3) record-keeping, 4) staying active, 5) education and careers, and 6) coping in everyday life. These topics are consistent with information and feature categories identified in other health apps currently available and the objectives originally established for the app. Brainstorming sheets for each topic were provided to and filled out by participants and then reviewed by the group.

Outcomes
The following feature ideas for the app emerged from the workshop, classified by participants according to the eight pre-identified categories:

Physical. A symptom-tracking feature was desirable. Two different navigational approaches to symptom tracking were presented. Discussion focused on the importance of linking the tracking experience with the knowledge-gathering experience. Seventy-one percent of participants deemed this feature as “must have.”

Emotional. Some participants felt that a feature outlining common myths and frequently asked questions about lupus could alleviate anxiety. Incorporation of links to more de-
tailed summaries and a quiz/gamification component were also considered. During the discussion, some participants expressed concern that this feature would not likely be revisited once initially read. Fourteen percent of the participants identified this feature as “must have” and 50% said it was “should have.”

**Intellectual (knowledge-seeking).** Pop-up informational tips and/or summaries were viewed as key features. Two different styles of dissemination were considered, both of which were connected to symptom tracking. Participants felt it was important that users not be inundated with text and that information offered should be relevant to individual user symptoms. Different formats for conveying information were also considered (e.g., audio, video, etc.). Sixty-four percent of participants regarded this type of informational feature as a “must have.”

**Social.** The participants felt that a social media component was important for establishing a sense of community and fostering a support system among teens with lupus. This could take the form of a link to established social media forums (e.g., Facebook or Twitter) with lupus-based groups built into the app. Concerns about privacy and abuse were raised. Fifty-four percent felt this feature was “must have” and 23% said it was “should have.”

**Practical.** A reminder feature to help teens manage their medications and appointments independently was suggested in which users would input information about their medications (e.g., purpose, dosage, schedule, etc.) and appointments (e.g., care provider names and locations and other contact information, etc.) and set reminder notifications. This was deemed essential—a “must have” feature—by 100% of workshop participants.

**Technical.** The participants felt that easy navigation was an important element of the user experience. The ability to access features within three clicks was deemed ideal. Menu styles and the notion of adaptability (whereby the app could be designed to anticipate user demands based on past usage patterns) were also discussed. Eighty-six percent of participants regarded easy navigation as a “must have” feature.

**System.** Participants felt that it would be helpful for teens to have a record of their medical history at hand. This could take the form of a summary log or be based on MyHealth Passport (www.sickkids.ca/myhealthpassport). Various methods of inputting user information were considered (e.g., directly into the app, to a profile on a computer, etc.). The medical history could also include a log or summary of the most recent symptoms. Sixty-four percent of participants felt this feature was a “must have” and 29% thought it was a “could have.”

**Miscellaneous (personalization).** During brainstorming, the theme of personalization emerged repeatedly. To enhance usage, the participants felt that customizability was an important component of the design. Suggested features for personalization included the option to add photos or select various sound effects, “skins,” or wallpaper templates.

One additional outcome was the decision to choose a new name for the app in future, in response to the strong dislike of the original name (“MyLupus App”) expressed by the younger workshop participants.

**DISCUSSION**

The methodology for developing a health app outlined above could be useful for the development of similar health apps. The authors believe the success of the method can be attributed to leveraging a range of respectful collaboration and contribution approaches.

Methods were chosen from the digital user experience body of knowledge and coupled with facilitation strategies intended to promote high-energy contributions and promote respect for each participant’s experience and voice. Participants’ knowledge base for both lupus and the digital user experience was built gradually and to a uniform level. Outputs included evolved use-case models, prioritized features with pseudo-requirements,10 user stories (to assist software developers in the interpretation of the pseudo-requirements), and visual navigation and interface concepts. Meeting pre-engagement was achieved through the assignment of reading and other homework and contributed to a “ready-to-go” attitude on the part of participants.

**Challenges and solutions**

There are many ways to develop a concept for a medical app. Traditional challenges include hearing the voices of various stakeholders as a collective rather than in a consultative process that is sequential. The methodology used for this app development project resolved this by implementing a face-to-face workshop and a variety of guided exercises led by an expert facilitator.

Creating an agenda that gradually built the knowledge base of participants was also essential to effective outcomes. To better inform their decision-making during software development, the software developer participants learned about lupus from those living with the condition and from health care professionals who adhered to meeting (workshop) guidelines to maintain discussion at the layperson level. Health care professionals and patients were exposed to software architecture and planning, also at a layperson level, which helped them realize the possibilities without curtailment ideation. The use of creative devices—such as drawing interfaces—fostered fun, engagement, and sustained energy. In addition, all participants used brainstorming techniques such as “brainwalking” and similar methods that celebrate all voices (15), which helped to ensure an inclusive process so that even those traditionally shy, quiet, or easily intimidated by “professionals” felt confident to contribute.

One possible limitation of the development process was the lack of participation of a parent of a child with lupus. However, the younger participants living with lupus indicated that this might have been a strength; they wanted the app to be truly “theirs” and had concerns about parental access to their information, something that they thought parents might want included.

As the methodology described above could be used to develop apps for other health conditions, certain challenges of the process should be noted. First, quite a bit of time was spent in helping the software experts understand lupus and its treatment. Similarly, the participants with expertise in lupus were given help to better understand mobile apps and...
their corresponding language. Although it was time-consuming, this step should not be skipped, as it was clear that neither group really understood the other’s issues before these discussions. Second, app development is expensive, and development of the lupus smartphone app included professional workshop facilitation plus an honorarium for each of the younger participants living with lupus. Therefore, for financial reasons, the app was developed for use with only one operating system. For future development of similar eHealth apps, procuring sufficient funding to enable compatibility with multiple systems is recommended.

Conclusions

Despite the challenges described above, the authors consider the development of the lupus smartphone app a success. First-phase software development of the app is complete, as is beta testing at one site.

The authors hope that others will use processes similar to the one described above to develop eHealth technology in a way that is inclusive, enjoyable, and productive.

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REFERENCES


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Uno de los desafíos tradicionales durante el desarrollo de una aplicación médica es considerar las opiniones de los diversos interesados directos como colectivo, en lugar de emplear un proceso de consulta de tipo secuencial. En este informe se describe el desarrollo de una aplicación para teléfonos móviles inteligentes dirigida a adolescentes con lupus, así como el procedimiento empleado para superar este tipo de dificultades. En el desarrollo de esta aplicación se buscó la mejor manera de incorporar información acerca de: 1) el lupus, incluidos los efectos tanto de la enfermedad como de los medicamentos utilizados para su tratamiento; 2) cómo las opciones de vida pueden afectar a la situación de los pacientes con lupus; y 3) los procedimientos para aumentar el autotratamiento y la comunicación. En un taller de dos días, en el que participaron diversos interesados directos (de 16 a 59 años de edad), se empleó una metodología colaborativa de generación de conceptos y recopilación de requisitos con el propósito de aprovechar los métodos de diseño centrados en el usuario para que sirvian de guía a los productores de aplicaciones para telefonía móvil. El proceso de desarrollo de la aplicación que se llevó a cabo durante el taller utilizó los siguientes pasos: 1) captar un grupo colaborativo centrado en las metas, 2) definir los objetivos de la aplicación, 3) evaluar las posibles necesidades de los usuarios, 4) hacer una lluvia de ideas sobre las características de la aplicación y elaborar modelos de casos de uso, 5) analizar las características y los prototipos de las aplicaciones existentes, 6) perfeccionar las funcionalidades, 7) redactar distintas experiencias de los usuarios, 8) visualizar el diseño de la navegación y las funcionalidades, y 9) determinar el contenido. El uso de recursos creativos como las interfaces para dibujar fomentó la diversidad, la participación y la energía sostenida; y el empleo de una técnica de lluvia de ideas permitió aprovechar algunos métodos que garantizaban un proceso inclusivo, de manera que aun los participantes tímidos, callados o fácilmente intimidables por los “profesionales” se sintieran cómodos para participar. Además del cambio de nombre de la aplicación, otro resultado del proyecto fue que se seleccionaron las siguientes características de la aplicación: seguimiento de síntomas; recordatorio de citas y medicación; un componente de redes sociales; un resumen del historial médico; navegación sencilla; contenido informativo; ludificación; y personalización (opciones de adaptación individualizada).

Palabras clave
Adolescente; lupus eritematoso sistémico; tecnología de la información; informática.