Meeting report: patient and caregiver recommendations for a mobile health application for paediatric systemic lupus erythematosus

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ABSTRACT

Paediatric systemic lupus erythematosus (pSLE) management and research could be enhanced by a mobile health application (app); however, no app designed for pSLE is currently available. A development and design committee comprising of patients, parents/caregivers and other stakeholders met to inform development and design of an app specific for pSLE. This meeting report summarises the group's discussions and recommendations that could help create a useful and desirable app or mobile health tool for the pSLE community.

INTRODUCTION

This report summarises discussion and recommendations from a virtual workshop held between February and May of 2023 as part of a Lupus Foundation of America-funded project. The project proposes to use mobile health or application (app)-based technology to study medication adherence in paediatric systemic lupus erythematosus (pSLE). The purpose of the workshop was to: (1) assemble an app development and design committee comprising potential app users and stakeholders, (2) align research goals with requirements of pSLE community members and (3) provide specific guidance and recommendations for a potential app for pSLE management and research.

Background and rationale

Managing lupus is complex and often requires strict adherence to complicated medication regimens for disease control.[1] Young patients with pSLE encounter added challenges of especially severe disease,[2] high rates of mental health comorbidities[3] and age-related developmental and psychosocial changes.[4 5] Apps can improve medication adherence and enhance management of other paediatric

chronic diseases,[6 7] and technologies have successfully been used in pSLE.[8 9] Yet, there remains a lack of mobile health or app-based technology tailored to the specific needs of the pSLE community. Ideally, an app would be designed by patients for patients with pSLE and simultaneously meet the needs for lupus management and research.

Overview of meeting content

A total of 13 individuals participated in the workshop. Participants included eight advisors, comprising three adolescent/young adult pSLE patients, three parents/caregivers and two adult lupus patients, including one with paediatric-onset disease. The workshop also involved a patient engagement specialist, a user experience design consultant, two pSLE physicians/researchers and a medical student. The workshop began with a kickoff session, in which introductions were made and project requirements and expectations were reviewed. Subsequent sessions were organised around key objectives, as outlined in figure 1. Each session was about 1 hour long and was conducted by teleconference (Zoom).

The first session was open discussion using the following prompts: *How has lupus affected your life and your loved ones? How do you manage lupus, including lupus medications?*

Each advisor shared their journey with lupus and the ways it has impacted physical, emotional and functional aspects of their lives. Each journey was unique, but common themes emerged. Advisors remarked that lupus changed their life trajectories, caused them to become more dependent on others and hindered their participation in daily and extracurricular activities. Many struggled with fatigue, joint pain, hair loss, rashes, weight loss and neurocognitive changes. They
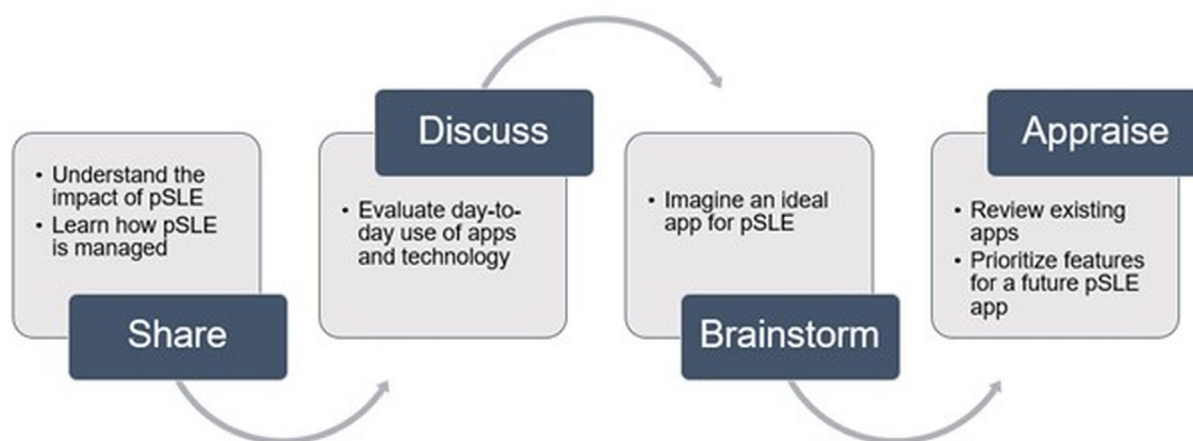
Figure 1 Overview of workshop activities and process. Each box represents one session and its major objectives. app(s), mobile health application(s); pSLE, paediatric systemic lupus erythematosus.

noted common triggers, such as changes in the weather, stress and diet. Advisors shared a variety of strategies to manage lupus, including taking medications and implementing lifestyle changes, such as ensuring adequate rest, improving nutrition, exercising, avoiding triggers and making necessary accommodations for work and school. Mental healthcare was highlighted as essential to managing lupus. Specific management tasks mentioned were participating in therapy, seeking care from a psychiatrist, working through the grief cycle and thinking positive affirmations. Advisors agreed the following skills are of paramount importance to managing lupus: learning when to say no, focusing on what can be achieved instead of what cannot be achieved and accepting support when necessary. For daily medication management, advisors described individualised approaches using tools including pill boxes, calendars and commercially available medication-tracking apps. A few advisors found note-taking apps helpful to record medication details such as date, prescribing provider, dosage and frequency and to log symptoms and store photos of lupus rashes.

The following session continued open discussion with additional prompts: *How do you use apps in general? What apps are (or could be) helpful to manage lupus?* Advisors described their experiences with apps they use regularly. In general, social, gaming and mindfulness apps were most enjoyable, while organisational and business-oriented communication apps were less enjoyable. Advisors disliked apps with advertisements, profuse notifications and excess channels to toggle between. Advisors were already using several different apps to help with lupus management tasks. These apps included weather apps (to track UV index, temperature and humidity), health apps (to track weight, water intake, blood sugar and physical activity), pharmacy apps (to manage prescriptions), social apps (to connect with other lupus patients for mental and emotional support), calendar apps (to track appointments) and note-taking and photo apps (to document and track symptoms). Advisors desired a single, intuitive app that would manage all lupus-related

tasks. Ideally, this app would allow seamless information sharing between the patient (app user), caregiver(s) and healthcare professionals. Desired features and functions included: storing individual health information (medical history, medication information, healthcare provider contact information), tracking symptoms and medications in real time, offering links to online resources and support groups and providing notifications/reminders for attending appointments, exercising, taking medications and refilling prescriptions. Advisors proposed an option to share health information with caregivers and notify caregivers if a medication is not taken.

The next session was dedicated to *brainstorming a 'dream app' for pSLE.* All advisors agreed that the app would need real-time symptom tracking. Advisors would like to use symptom tracking to communicate with their healthcare providers and identify triggers of increased lupus symptoms. Advisors also deemed medication tracking and medication reminders one of the most important features. The ideal app would organise medication names, dosages and frequencies, provide notifications for when medications must be taken and send reminders for when prescriptions should be refilled. Advisors noted lupus medication management can be complex, presenting challenges when using an app. Specific challenges and suggested solutions are summarised in table 1. Advisors recommended that the app offers a convenient drop-down menu of the most common lupus medications. Advisors also suggested an archive of prior medications for easy reactivation, along with the ability to document any allergies or adverse reactions to archived medications. Regarding notifications, advisors said these need to be difficult to dismiss, so the alert is acted on at the time of notification (ie, taking medication when it is due). A dream app would also provide a calendar for appointments across multiple providers and institutions. If possible, the information in the lupus app would be easily integrated with other apps. The information in the app would be consolidated into a printable health

Table 1 Paediatric systemic lupus erythematosus patient-generated and caregiver-generated solutions to specific challenges using a mobile health application (app) to manage lupus medications

Challenges	Suggested solutions
Lupus medication regimens are often complex. Entering several medications into an app can be time-intensive and frustrating.	▶ Provide a drop-down list of common lupus medications and dosages. ▶ Allow 'custom' or 'other' option for all fields when manually entering a medication. ▶ Sync medication list to healthcare or pharmacy records. ▶ Use image-to-text to prepopulate information from a pill bottle. ▶ Add an option for a picture alongside each medication.
Lupus medications are often changed, removed or added back. It can be difficult to remember why these changes were made.	▶ Create a medication archive where prior medications can be saved and easily reactivated in the future. ▶ Provide an option to save notes whenever a medication is archived (eg, adverse reaction, ineffective, too expensive). ▶ Generate an easily printable or exportable list to share with healthcare providers and caregivers.
Many people with lupus take medications multiple times per day. Receiving individual notifications for each medication is overwhelming.	▶ Present multiple options for notifications, in addition to off/on. Users may want or need different frequencies of notifications at different times over the course of illness.
Lupus is often managed by a patient and parent/caregiver, but apps are typically created with one user in mind.	▶ Create linked accounts for the app, with one account for the patient and another account for the parent/caregiver. Who can view and edit the app should be flexible. Sometimes the patient will enter information, but sometimes the parent/caregiver will need to enter additional or override information. It would be helpful for the parent/caregiver to view data so they know when to intervene. ▶ Provide an area for private notes for each account.

report format that could be shared with their healthcare providers. Finally, a dream app would be intuitive with an easy-to-use interface. Ease of use is especially important during disease flares or brain fog episodes from lupus.

Advisors had a nuanced discussion around access within the app. There was agreement that an ideal app would target adolescents with pSLE and their parents/caregivers. Adolescents with pSLE would primarily enter and view information in the app, but caregivers could view and potentially edit information as well. Settings should be based on the age of the patient. For younger users, the parent/caregiver(s) should have access to most or all information. Once the user turns 18, the user would choose who gets access to their information. Even after the user turns 18, there should be a legacy contact within the app in case of an emergency (eg, if the user loses consciousness). Advisors discussed that an app could be a powerful tool to help young patients communicate with their parent/caregiver(s). For example, an adolescent with pSLE could use the app to learn about lupus and develop self-management skills, while a parent/caregiver could use the app to view the adolescent's trends in symptoms, monitor adherence to medication and determine when to intervene with lupus management.

Overall, a dream app for lupus would be a 'one-stop shop' for all lupus-related activities. It would track symptoms and medications, aid with different health-related tasks and provide a comprehensive overview of the user's health and lifestyle. A dream app would help users communicate with their caregivers and healthcare providers and work together to lessen their overall disease activity.

The final session was an *appraisal of existing lupus apps and prioritisation of key features for a new app.* Prior to meeting, the lead researcher identified existing lupus apps by searching the Apple and Google Play App stores for 'lupus', 'SLE' and 'systemic lupus erythematosus.' Specific apps reported in medical literature were also queried by name.[10–12] Only two lupus apps were fully functional and free for download at the time. Advisors volunteered to download and rate the apps. Results are shown in figure 2. During the final session, advisors discussed both apps and noted outdated interfaces, sluggish performance and absence of features like caregiver participation. It was clear that current apps did not meet expectations of advisors and were lacking many features that would be critical for managing pSLE. Advisors then reviewed a list of suggested functions and features for a pSLE app and voted on the most important features. Medication and symptom tracking were tied as the most important features, followed by (in order) organising laboratory results and providing an integrated calendar for healthcare appointments. These observations underscore the need for a modern, comprehensive app that incorporates the needs of patients and caregivers in the pSLE community.
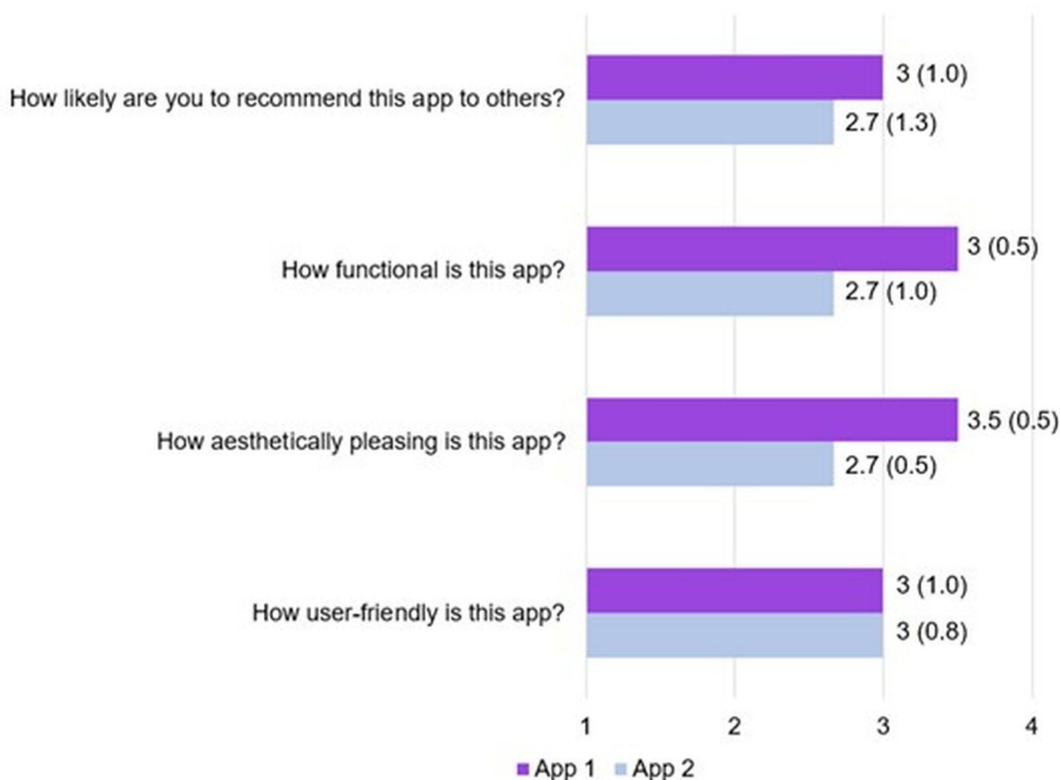
Figure 2 Mean (SD) ratings of two existing mobile health applications (app(s)) for lupus. Apps were rated by three paediatric lupus patients and parents/caregivers using a scale of 1–5 with 1=lowest and 5=highest rating.

KEY FINDINGS AND DISCUSSION

Advisors expressed great interest in an app customised for pSLE, especially an app that would be a 'one-stop shop' for managing all lupus-related tasks. Numerous features and functions were identified as useful or potentially useful for lupus management; overall, real-time symptom and medication trackers were most important, followed by organisational tools for laboratory results and appointments. Recommendations align with a similar project conducted more than 10 years ago,[12] indicating an ongoing, unmet need for technology customised to pSLE. Indeed, in absence of a current, universal solution, many advisors reported using multiple apps simultaneously to support various aspects of lupus management. Using several simultaneous apps was cumbersome, frustrating and often ineffective. Because each lupus experience is unique, an ideal app would offer several features and functions that could be customised to each user to meet their specific needs.

Incorporating parents/caregivers is a critical technological need identified by this group. pSLE is typically managed by a patient–parent/caregiver dyad, and roles and responsibilities change over time.[5] Comanagement in an app could allow a parent/caregiver to supervise a young patient as they develop independent self-management skills and intervene when needed. Even after a patient turns 18, advisors identified several scenarios where it would be important for a caregiver to access the user's health information, like during a disease flare or emergency. Using an app to comanage lupus could be a great opportunity to improve the health of young patients with pSLE.

Traditional information collected as part of lupus research studies may be enhanced by data collected directly from patients/caregivers on an app. Symptom and medication tracking have been used to investigate the impact of medication adherence on symptoms, quality of life and healthcare utilisation in other chronic conditions.[13] Research apps have integrated into the electronic medical record and provided graphical summaries for healthcare providers, as suggested by the advisors.[14] Existing technology used to monitor weather, activity, sleep and water intake has been incorporated into various research apps.[15–17] Thus, health data amenable to app collection and identified as key for lupus management could simultaneously power research to improve care and outcomes for pSLE.

CONCLUSION

The development and design committee identified numerous opportunities for an app to aid in lupus management and suggested approaches to overcome challenges they have previously encountered when using apps. Data directly collected from patients/caregivers on an app could enhance and add a valuable perspective to lupus research. Specific recommendations can be incorporated into future projects

using mobile health technology to improve pSLE management and enhance research.

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