

Co-designing an app for children with periodic fever: the views of guardians, healthcare professionals and researchers

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Abstract

This paper reports on an ongoing interdisciplinary research and development project with the overall purpose of developing a mobile app and platform for monitoring fever episodes, symptoms, and infections in children with periodic fever. In this paper, the focus is on the co-design process, in which a prototype for registering and visualizing fever episodes has been developed, tested and evaluated for usability and functionality. The study takes a socio-technical approach and uses co-design as a method. This means that users and developers collaborate in the design process, an approach that has proven effective in creating user-friendly and relevant digital solutions in healthcare. The app was tested for usability, functionality, and clinical viability through a combination of AttrakDiff and System Usability Scale (SUS) questionnaires, along with qualitative feedback. Findings show that participants found the app easy to use, and that symptom registration and visualization, facilitated by the digital platform and mobile app, were viewed as useful and important from several perspectives. Guardians found the app valuable for managing recurring fever episodes and planning daily life better, which may positively influence compliance, help increase control, and reduce stress. From the healthcare professionals' perspective, digital symptom recording can provide a clear picture of disease progression and contribute to an earlier and more accurate diagnosis, as well as support the follow-up and evaluation of treatments. A shared understanding of symptoms and disease progression can also enhance communication among guardians, their children, and healthcare professionals, thereby increasing participation and improving the child's care. From a research perspective, continuous registration of symptoms enables improved data collection, and multidisciplinary collaboration has the potential to enable synergies between clinical work, development, innovation, and research.

Keywords

co-design, healthcare, mobile app, patient-generated health data, socio-technical perspective

1. Introduction

Remote patient monitoring (RPM), referring to the continuous tracking of health-related parameters outside traditional clinical settings, is part of the ongoing transition towards patient-centered care, and increasingly prioritized as a strategy to enhance patient care and reduce healthcare costs [1, 2]. Self-tracking practices initiated and driven by patients themselves, also known as the quantified self, have become widely used in people's daily lives [3, 4], allowing individuals to monitor and manage their health and well-being over time, and patients to take a more active part in decisions about their health and treatment [3, 5]. The growth of patient-generated health data and digitally empowered and engaged patients, while beneficial in many ways, also brings significant changes to healthcare practice, medical work, and the doctor-patient relationship [6]. Healthcare providers can also initiate RPM as a supplement to or replacement for standard care, where health professionals collect and

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analyze patient health data remotely and provide feedback on the reported data as part of treatment. The data, collected via apps, sensors, and wearables, may include both objective parameters and subjective assessments. The feedback can be generated automatically if the data falls within a predefined range [1, 2].

Remote patient monitoring has the potential to support patient autonomy, clinical decision-making, and collaborative care [7]. It can decrease hospital visits and improve access, especially for chronic conditions, such as hypertension, diabetes, and chronic obstructive pulmonary disease, and elderly patients [8]. In digital mental healthcare, platforms and wearable technologies have been found to foster empowerment and contribute to overall well-being by enabling more active participation in care for patients with bipolar disorder and schizophrenia, along with the healthcare professionals treating them [9]. However, self-management tools may also increase anxiety symptoms among patients, and there is a risk for, on the one hand, mistrust, and on the other, overreliance on RPM systems [10]. Like other health information systems, remote patient monitoring presents complex, dynamic, and socio-technical challenges, and thus requires a design approach that takes into account patients, providers, and the implementation setting [1, 11-13]. Design recommendations for patient-generated health data include providing dynamic visual representations as well as static snapshots of PGHD to both patients and clinicians [14].

Periodic fever, aphthous stomatitis, pharyngitis, and cervical adenitis (PFAPA) syndrome is a rare autoinflammatory disorder characterized by recurring episodes of fever and other symptoms. It primarily affects children, and the exact causes are still largely unknown [15]. The nature of PFAPA can significantly impact the quality of life for both children and their families, especially before official diagnosis. The mechanism, diagnosis, and treatment of PFAPA and other autoinflammatory diseases offer valuable insights into these complex conditions, underscoring the need for further studies to enhance our understanding and develop more effective treatment strategies, which are beneficial to researchers, clinicians, and families of children with PFAPA [16]. Many guardians describe living in a state of uncertainty, frantically searching for answers. The frequent fever attacks make it difficult for caretakers to recall past episodes, resulting in memory bias, which underscores the importance of finding effective ways to monitor and manage the condition [17]

In this paper, we focus on RPM initiated by healthcare, more specifically on the co-design process of a mobile app for monitoring fever episodes, symptoms and infections in children with periodic fever, PFAPA. Initial findings suggest that closely monitoring fever episodes over an extended period has benefits, including characterizing fever episodes, facilitating diagnosis, and studying disease progression in PFAPA. However, it is challenging for caregivers to maintain continuous documentation. An app could enable the gathering of data on periodic fever episodes, which can help in understanding the regularity and severity of the illness, increase engagement, and promote patient empowerment while enhancing treatment adherence [16, 18]. Through active collaboration with guardians and healthcare professionals, the project aims to ensure the app meets user needs and supports clinical care, communication, and research. This paper reports on the methodological part of the study, focusing on the co-design process. In particular, the aims of this study are to:

- 1) Assess the views of guardians, healthcare professionals, and researchers regarding the design and usefulness of an app for collecting health data to monitor fever episodes, symptoms, and infections to overview the disease and its progression;
- 2) Develop an app using co-design as a method; and
- 3) Testing and evaluating the app through a combination of AttrakDiff and System Usability Scale (SUS), along with qualitative user feedback.

2. Methods

The design approach is co-design, following the methodology outlined in [11]. The following section describes the research setting and participants, outlining the development phase of the app, followed by a description of user tests, data gathering, and analysis.

2.1. Study setting and participants

The research setting is within Swedish healthcare, at one of the larger non-university hospital groups, comprising three hospitals and approximately 5,000 employees that provide healthcare and medical services to 270,000 inhabitants. The research team includes pediatricians, researchers, and developers who have established an interdisciplinary research and development collaboration encompassing pediatrics, immunology, epidemiology, systems science, informatics, and learning. The project received funding, in the form of a student innovation grant, to create an app designed to track sick days and symptoms in children with PFAPA. The result was a prototype of a mobile app and a digital platform that enables doctors to quickly assess their patients' health data. Based on a qualitative approach, drawing on interview data, extended to guardians and children without PFAPA, and the co-design method, these initial findings show that specific app features can help with compliance while reducing memory bias [16] and improve communication between guardians and pediatricians, by encouraging collaboration and personalized disease management through guardian and healthcare professional co-creation [18].

The study takes a socio-technical approach, in which technical and social aspects, and their mutual relationship, are taken into account [12]. Following the co-design approach [11] involves including and actively engaging all relevant stakeholders in the design process by sharing their experiences, insights, and expertise. In this case, the guardians and their children and their treating healthcare professionals, researchers and system developers, as well as other roles such as policymakers and hospital IT and security personnel. This paper focuses on the design, development, and usability of the digital platform and mobile app, based mainly on a three-month pilot study and the app's usability from the viewpoints of guardians, healthcare professionals, and researchers. Guardians of children with PFAPA were recruited consecutively from the participating hospitals to ensure good representativeness, and pediatricians involved are those with the most experience in clinical work with PFAPA and other autoinflammatory diseases. A control group of children in the same age span, but without PFAPA, was also recruited, and a brief pre-test was conducted with volunteer guardians before the pilot study began (see Table 1).

Table 1
Overview of user characteristics and user testing.

User	App version	Smartphone	Group
1	Not PFAPA	iPhone	pre-test
2	Not PFAPA	iPhone	pre-test
3	Not PFAPA	iPhone	pre-test
4	Not PFAPA	iPhone	pre-test
5	PFAPA	iPhone	pre-test
6	Not PFAPA	iPhone	pre-test
7	PFAPA	Android	pre-test
8	PFAPA	Android	pre-test
9	Not PFAPA	Android	pre-test
10	PFAPA	iPhone	pfapa-pilot
11	PFAPA	iPhone	pfapa-pilot
12	PFAPA	Android	pfapa-pilot
13	PFAPA	Android	pfapa-pilot
14	PFAPA	iPhone	pfapa-pilot
15	Not PFAPA	Android	control-pilot
16	Not PFAPA	iPhone	control-pilot
17	PFAPA	Android	pfapa-pilot
18	PFAPA	Android	pfapa-pilot
19	Not PFAPA	iPhone	control-pilot
20	Not PFAPA	Android	control-pilot
21	Not PFAPA	Android	control-pilot

There was a fairly even distribution between male and female guardians, as well as between iOS and Android users across the groups. They represent users with moderate to high digital literacy,

meaning they were generally comfortable using mobile apps but not necessarily advanced or expert users. Participants were included after consenting to register in the mobile app and to participate in the evaluation of its functionality. They were encouraged to register daily, regardless of whether the child showed symptoms or not, and were reminded weekly in cases where no registrations had been made during the past week.

2.2. Development process and environment

This section describes the technological environment for developing the app, starting with the front-end, then the back-end, and the database connection, and how it was implemented. The three layers of the app were as follows: the UI layer used React Native and was written in TypeScript. React Native is a cross-platform library developed by Meta (formerly Facebook) that enables developers to use JavaScript or TypeScript to write a mobile app for both iOS and Android simultaneously. It is a robust and widely used library, making it the obvious choice for this project. The logic layer was written in C# using the .NET Framework. C# and .NET are both made by Microsoft and have a reputation for being stable and maintainable. Finally, SQLite 3 was used for the repository layer, due to its simplicity. The solution ran smoothly in the development environment, but additional work was required to scale and deploy it to testers. The digital platform utilized many of the same technologies, with React being employed for the UI layer instead of React Native, as the digital platform is designed to run within the end user's web browser.

To conduct user testing, the app needed to be deployed on the users' devices. In mobile development, this is possible through Apple's TestFlight for iOS users and the Google Play console for Android users (see figure 1)

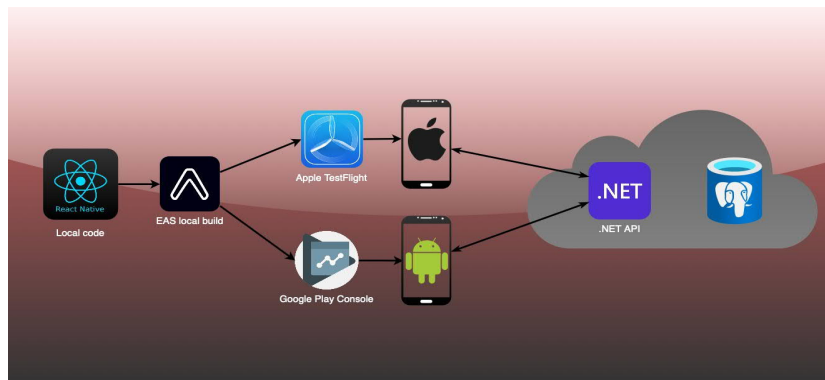


Figure 1: A diagram of the app's journey from local code to test users.

The development of digital health technologies, such as mobile health apps, also involves regulatory and legal considerations to ensure compliance and protect patient data. In Swedish healthcare, which is the setting for this study, the most important regulations include the General Data Protection Regulation (GDPR), governing the processing and storage of personal data within the European Union, and the Patient Data Act (PDL), which supplements GDPR with specific provisions applicable to handling personal data in healthcare settings. Besides ensuring legal compliance, the app must also adhere to strict information security standards to protect sensitive health data. In this study, all data processing is conducted in accordance with GDPR, with data stored on a secure server managed by the hospital's IT department. To ensure the app's approval within the hospital's IT environment prior to deployment, separate information classification and risk analysis were also conducted. The information classification was carried out to assess the need for data protection in the app and was documented in accordance with the hospital's regional procedures. Personal data (pseudonymized) in the Fever App was assessed as protected information, with moderate to significant consequences according to the criteria of confidentiality, traceability, availability, and accuracy. The risk analysis aimed to identify threats and vulnerabilities, and assess

and manage associated risks. Identified risks included potential technical issues and difficulties accessing data, which could impact the research study's outcomes. These risks were considered acceptable after mitigation.

Ongoing discussions were held with the project's system developers and the regional IT architect regarding data storage and the handling of personal data. In consultation, a decision was made to use secure cloud storage (Azure) and to conduct the pilot study in a test environment using TestFlight. To meet ethical guidelines, personally identifiable information has been removed and replaced with a Research ID, which is shared across solutions. The database was migrated and is shared between the Web and Mobile APIs, running in a deployable Docker container, as shown in Figure 2. During the project, the digital platform used by health professionals was later migrated to a web interface using Power BI, a solution provided by and integrated with the hospital's internal IT infrastructure.

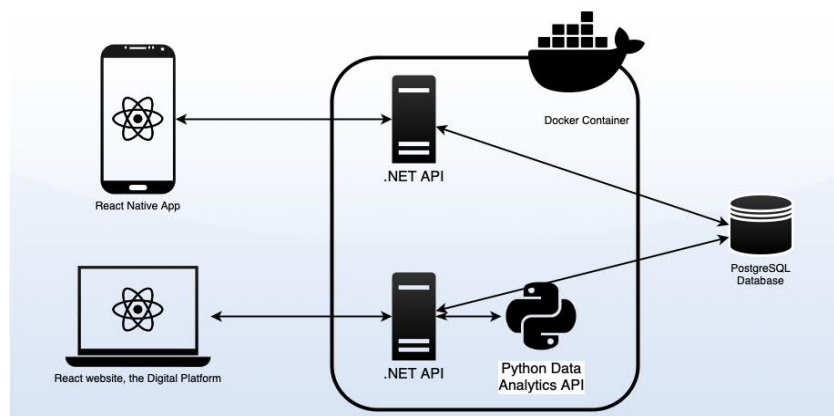


Figure 2: A diagram of solutions

2.3. Co-design and user testing

The co-design process involved extensive engagement with health professionals, including pediatricians (who held dual roles as clinicians and researchers), the research nurse in the project, and guardians of children with and without PFAPA. This engagement gathered user needs and requirements, ultimately leading to the development of a functioning prototype of the app. The prototype app, developed for use in the methodological study, has been given the working name “Periodic Fever App” (PFapp). The app has been continuously tested by the research team and volunteer guardians, and feedback has been provided to the developers in an iterative process that will continue until the app achieves optimal functionality. During summer 2024, the prototype app for the methodological pilot study was finalized after being designed, developed, and tested by the research group’s system developers, pediatricians, and informatics experts (see Figure 3).

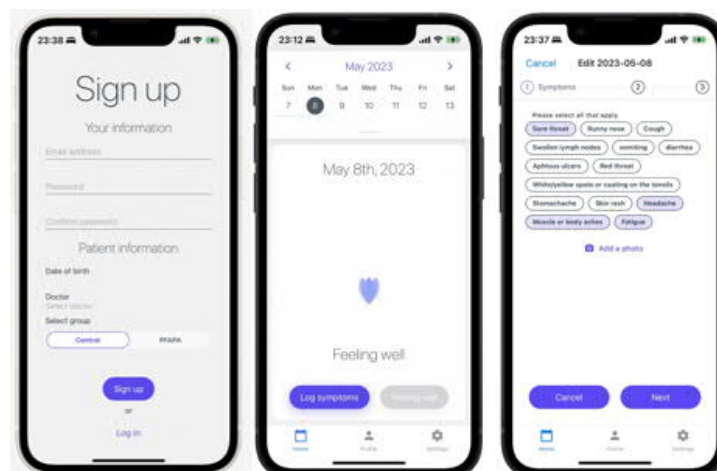


Figure 3: Prototype screenshots for user tests

Before the pre-test and pilot study, the app was translated into Swedish. In this phase, users were given access to the app, along with tasks to solve, with the purpose of gathering qualitative and quantitative feedback. The participants were asked to fill out feedback surveys (pre-test group), using validated questionnaires (AttrakDiff and SUS), combined with interviews (pfapa/control pilot groups) which included the “think-aloud” method [19] in which the participants were encouraged to think aloud and describe what they were doing or expected to be able to do while using the app. Healthcare professionals with expertise in PFAPA were also given access to the app and digital platform and asked to analyze the different tasks and provide feedback and suggestions for improvement. As they interacted with the app, they were asked to critically assess various aspects, including user interface, navigation, content, accuracy, and overall usefulness in their daily practice. After completion of all user tests, results and comments were collected and summarized to draw conclusions and draft improvements in design, user experience, and functionality. Overall scores from the usability surveys were above average, although there was room for improvement in areas such as hedonic quality (how the app stimulates the user), engagement, and enjoyment. Qualitative feedback from health professionals contributed to enhancing the app’s clinical relevance, functionality, and data integrity. The findings are detailed and further discussed in the following sections.

3. Findings

The presentation of the findings follows the co-design process, beginning with a summary of the identified user needs and requirements, along with user comments and specific suggestions for improvement. This is then followed by a presentation of the design modifications and improvements made to the digital platform and app, based on the results of the user testing.

Overall, the user tests provided valuable feedback on how participants interacted with the app and the issues they encountered while using it. The app received relatively high usability scores, supported by qualitative feedback regarding the usefulness of the app. The finding that participants found the app to be fairly task-oriented was expected and desirable, as the app is designed to provide a solution for the specific task of logging sick days for children with periodic fever. However, lower scores in the hedonic quality dimensions suggest that the app could enhance its ability to engage users, highlighting the need to strike a balance between task-focused design and user engagement and enjoyment. The usability testing revealed a shared expectation among participants for a simple and easy-to-navigate user interface. During the pre-test, several participants experienced issues with the installation process, related to logging in and accessing the app. This was addressed by simplifying the process and providing a user manual and support. However, after downloading and using the app, users generally found it to be intuitive, user-friendly and easy to navigate. The participants emphasized the importance of clarity and ease of navigation. They stressed the need for a simple and intuitive interface: “It should be simple—the simpler it is for someone who isn't tech-savvy, the better for all” (user quote from survey). The qualitative feedback on the app, including bug reports and improvement suggestions, helped us identify potential issues and areas for enhancement. By incorporating input from medical experts, we ensured the app aligns with the specific needs and expectations of its target users, ultimately leading to better user satisfaction and adoption.

The quantitative and qualitative feedback from survey questionnaires, open-ended questions, and interviews, including comments and suggestions made by users during the tests, informed the design and development of the digital platform and the app, as well as guided improvements and redesigns. For example, in response to the feedback, the app’s interface was simplified to ensure consistency across similar features, and the calendar marking system was refined to offer a clear overview of historical data. Dialog screens and navigation paths were also revised, and the sign-up process was made more intuitive. After clinicians requested the addition of new symptoms, the log view became

cluttered. This issue was resolved by using a wizard – a UI element that guides the user through a sequence of steps, dividing the process into smaller, more manageable steps. This design enables users to easily see which steps remain and which have been completed, creating a clear and intuitive user experience that responds to their needs.

In summary, many of these suggestions from the qualitative feedback and comments for improvements aligned with what was found during initial user testing and were taken into account when improving the app. Some features, such as a photo-sharing option or a digital fever thermometer, were technically possible but not implemented due to legal and patient safety concerns. The option to add free-text symptoms was not implemented due to the need for significant database updates. Other than that, all suggestions were addressed. An overview of the steps and functions in the app is provided in Figures 4a and 4b, below. Based on feedback from user tests regarding usability and user experience, and in accordance with clinical feedback, the process was divided into the following steps: *Symptoms* allow the user to select the present symptoms by tapping on the corresponding chips. *Temperature* lets the user choose the daily temperature and label it as estimated or measured. *Diagnosis*: For PFAPA, it asks whether the guardians considers this a PFAPA episode and whether the child has received a diagnosis and/or treatment from a doctor. If yes, the guardian is asked to select a diagnosis and, optionally, enter treatment as free text. If not, the guardian is asked how they would classify the symptoms. In the case of diagnosis and classification, the guardian can select 'other,' allowing them to write in a free-text diagnosis or classification. Here, the user also saves the symptoms. The *profile* view displays the information panel, where the user can view the research ID and share it with the doctor. The *calendar* view indicates whether a date has been logged and clearly shows periods of logged good days and periods of fever or other illnesses. The expandable calendar displays periods of fever in red, healthy days in green, and the corresponding dates.

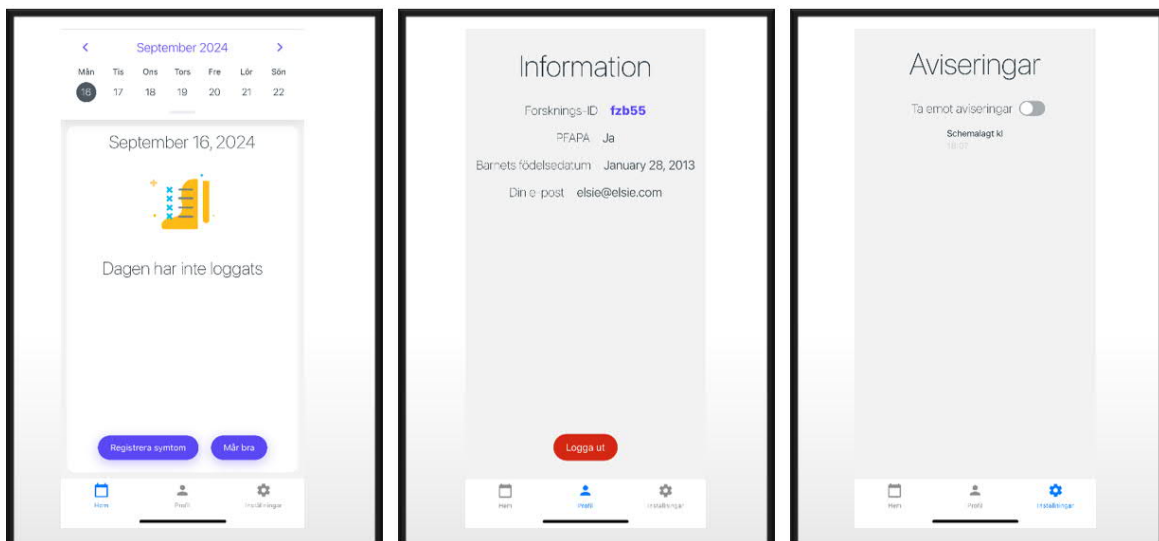


Figure 4a. Screenshots of the app: The Home screen (left) displays the calendar with options to log symptoms. The Profile (middle) shows an information panel with the research ID. The Settings (right) allow turning notifications on/off and selecting a time for reminder notifications.

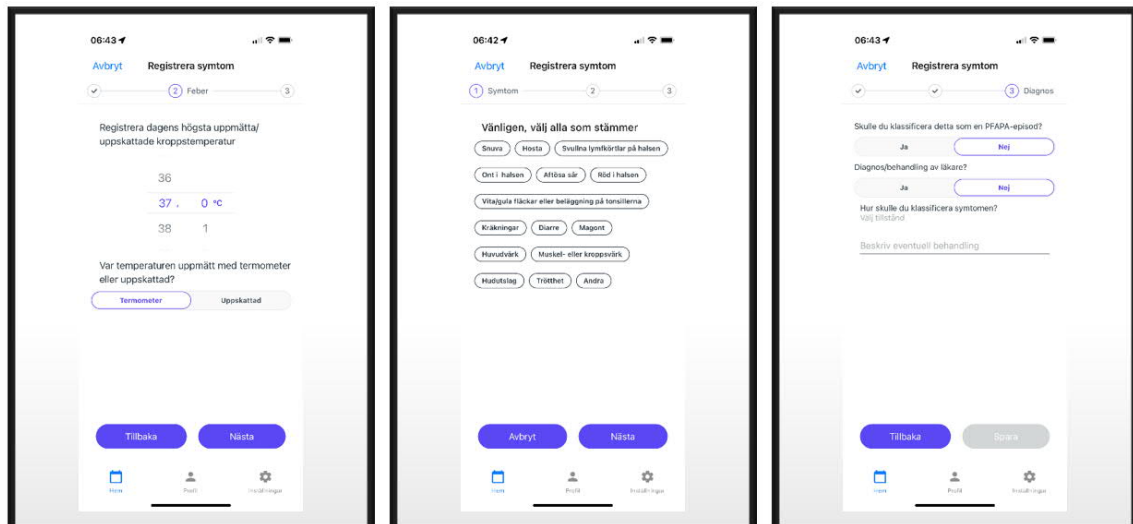


Figure 4b. Screenshots of the app: Fever registration (left), Symptom registration (middle), and Symptom classification (right) with the option to add any treatment and save the entry.

The Digital Platform (see Figure 5) is primarily designed for research, intended for health professionals to quickly access an overview of patient health data and recorded symptoms, supporting research by systematically collecting symptom data in children with PFAPA. Data is automatically transferred from Pfapp to the digital platform, allowing real-time analysis of disease patterns, infection frequency, and seasonal immune variations. The study compares children with PFAPA to healthy controls to better understand the condition and explore the hypothesis that PFAPA may have offered an evolutionary advantage during times of high viral mortality. While designed for research, Pfapp and the digital platform also benefit clinical care. The input gathered from medical experts has strengthened the app's clinical relevance, making it more suitable for supporting patients and healthcare providers in tracking and managing symptoms, while creating a de-identified dataset for research purposes. By helping guardians monitor symptoms, plan ahead, and feel more in control, findings indicate an improved quality of life, reduced stress, and better communication with healthcare providers. Based on user feedback regarding requirements for clinical use and research, the digital platform has been enhanced to display the new research ID for all patients, replacing the old name and other identifying details. The patient details view displays a zoomable timeline of fever since the user started logging. When hovered over, it shows the relevant information for the nearest day: fever, diagnosis, and symptoms if sick; date and 'feeling well' if logged as such; and date and 'not logged' if the date has not been logged. Additionally, a table below the chart displays the sick episodes and healthy periods, which can be hovered over to highlight the relevant part of the timeline chart, as shown in Figure 5.

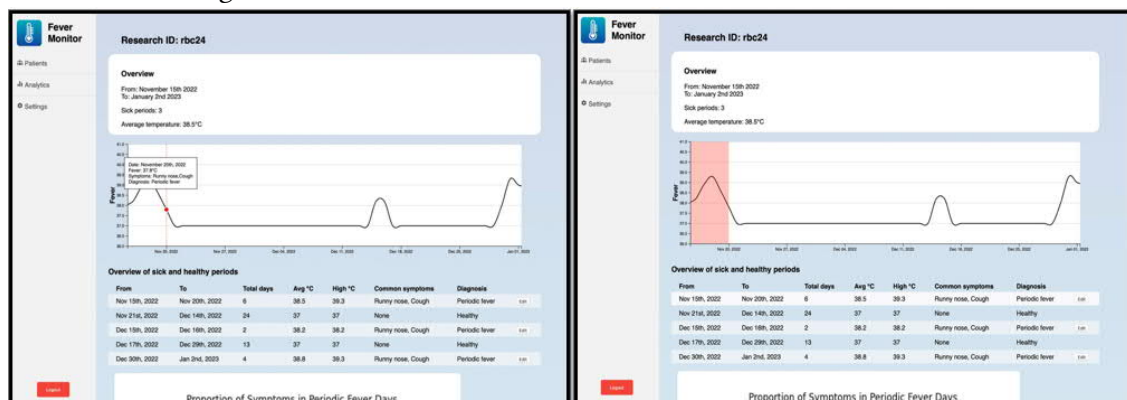


Figure 5. The digital platform displays details for each day when the timeline is hovered over (left). It is highlighted on the timeline chart (right), with green indicating a healthy status and red indicating an unhealthy status.

In sum, our study found that guardians and health professionals share similar, positive experiences and attitudes towards using a mobile app to gather health data and monitor fever episodes, symptoms, and infections, as well as for research purposes where aggregated data is collected and analyzed to better understand the condition from an epidemiological perspective. The testing and evaluation of the mobile app provided insights into its usability, functionality, and clinical role. The usability questionnaires, open-ended survey questions, and qualitative feedback from guardians and medical experts demonstrated that the app was well-received by users and offers a reliable and user-friendly platform for managing and monitoring symptoms. The System Usability Scale (SUS), however, is not a diagnostic tool and therefore does not provide answers to why users are responding the way they do. Furthermore, the questionnaires focused on usability and aesthetics, which may not fully capture the clinical relevance or effectiveness of the app. Qualitative feedback from medical experts contributed to improving the app's clinical usefulness for patients and healthcare professionals, as well as data integrity and security for research purposes. This collaboration has ensured that the app meets the expectations of its target users and adheres to standards for user privacy and data collection for research purposes. Experiences from the co-design process highlight both the importance and challenges of interdisciplinary collaboration, emphasizing the need for clear communication and an agile, iterative approach in design and development.

4. Discussion

Patient engagement through patient-generated health data (PGHD), patient forums, and health apps has enabled patients to take a more active role in managing their health and well-being [6, 20, 21]. Previous research suggests that remote patient monitoring (RPM) has the potential to reduce healthcare costs, improve clinical decision-making, and increase patient engagement when well-designed and implemented in collaboration with patients and healthcare providers [1, 5, 7]. Following this approach, using co-design as a method, the overall goal of this ongoing project is to develop a digital platform and a mobile app for children with periodic fever so that guardians, health professionals, and researchers can monitor the disease and its progress. In this paper, we have reported on the methodological part, highlighting the importance of involving health professionals and patients, in this case, guardians and their children, in the design and development process. Based on the analysis of our findings, gained through the user testing and evaluation of the app, this section further discusses the findings and their implications from the perspectives of guardians, health professionals, and researchers.

First, the guardians' views on using a mobile app support and expand our initial findings, as well as the existing literature on co-design in healthcare, emphasizing its role in promoting increased patient engagement and collaboration [16, 18], empowering patients to participate in decision-making about their health and treatment [3, 5]. By systematically documenting symptoms, guardians can present a clearer picture of the disease to healthcare staff, enabling them to take a more active role in the investigation and care. This increases participation, strengthens the dialogue with caregivers, and improves the child's care, especially important in periodic fevers, as there are many differential diagnoses, which means the child is subjected to many tests and examinations [15]. From a usability standpoint, it is recommended to provide patients and clinicians with both dynamic visualizations and static snapshots of health data [14]. A mobile app, like Pfapp developed in this research, that provides a clear picture of the disease course can, therefore, help the child receive an accurate diagnosis earlier, thereby avoiding unnecessary investigative efforts, as well as allowing families to better plan their daily lives by mapping the disease pattern, which can contribute to increased control and reduce stress.

Secondly, for healthcare professionals, remote patient monitoring can facilitate better decision-making in clinical practice [7] and support shared decision-making based on patient-generated health data [22]. A digital platform and mobile app can help patients and medical professionals make informed clinical decisions based on health data collected; however, as our findings show, usability

and clinical relevance are crucial. The actual use of digital solutions in clinical practice remains limited. This is partly due to concerns about security and reliability when using apps in healthcare, as well as the fact that patients are rarely involved in the design process [20, 23]. A clear presentation of symptoms, disease picture, and disease course provides healthcare professionals with a more accurate basis for making diagnoses and guiding investigations. Additionally, the views of health professionals, as outlined in our findings, suggest that establishing a shared understanding of symptoms and the disease course helps improve communication between patients, caregivers, and guardians.

Thirdly, for researchers, continuous registration of symptoms has the benefit of improved data collection. Using patient-generated health data (PGHD) provides researchers with valuable insights into diseases such as periodic fever syndromes, as it enables the real-time and continuous tracking of symptoms and disease progression outside clinical settings. In line with initial findings and studies in other areas of healthcare, our results indicate that a mobile app can increase compliance and reduce memory bias [8, 9], thereby providing more accurate and longitudinal health data, which enhances the ability to study patterns such as infection frequency and seasonal immune variations. By integrating data from the mobile app into the digital platform, researchers can analyze larger datasets and test hypotheses, such as comparing children with and without PFAPA. Although primarily designed for research, the digital platform also promotes patient-centered approaches by aligning scientific inquiry with lived experiences, where interdisciplinary collaboration enables synergies among clinical work, development, innovation, and research.

To sum up, this research addresses the need for innovative digital health solutions that are co-designed with end-users and tailored to real-world clinical contexts. The paper concludes by proposing four design considerations for collecting and monitoring patient-generated health data remotely, offering practical guidelines for future development and implementation:

- **Minimize the learning curve and simplify repetitive tasks:** use standard, easily recognizable input methods so that users immediately understand what to do and don't spend unnecessary time learning the system. Group similar items and use familiar navigation methods.
- **Iterate with relevant stakeholders:** ensure that the design and features match the requirements of the end users of each system. In our study, these are the guardians of children, both with and without PFAPA (control and treatment groups), who will use the mobile app, as well as clinicians who will follow and evaluate the data collected through the digital platform. Catering to both groups is important to ensure that the data collected by the mobile app is accurate and detailed, and that the data visualizations meet the needs of the clinicians using the digital platform.
- **Emphasize security and data integrity:** focus on protecting patient data through strong security measures, anonymity, and maintaining data integrity. Involving expertise in legal and regulatory frameworks relevant to digital health and using robust frameworks and services to ensure security and data integrity is important, particularly in healthcare data management, as it helps protect users' identities and prevent personal information leaks.
- **Design for extensibility:** Design and develop the initial solution with the understanding that requirements are constantly evolving in today's world. It's important to plan for the inevitable scenario where a new service is needed to process or display data differently, and to make that process as seamless as possible.

5. Conclusion and next step

This interdisciplinary study presents the development and evaluation of a mobile app and digital platform for monitoring symptoms in children with PFAPA, using a socio-technical and co-design approach. The prototype was tested for usability, functionality, and clinical relevance through a combination of standardized questionnaires and qualitative feedback from guardians and healthcare professionals. Findings show strong support for the app's usefulness in everyday life, clinical

communication, and research, suggesting that it can improve communication and collaboration, increase engagement, and promote patient empowerment. From a research perspective, the mobile app and digital platform can facilitate and improve the gathering of structured health data throughout the course of the disease, which has not been done before and could lead to better healthcare for children with periodic fever in the long run. The paper concludes with four design considerations for remote monitoring of patient-generated health data. While the study was limited in scope and sample size, it lays the groundwork for a longitudinal study, where participants will continue to track their symptoms over time. This paper focused on the co-design process, primarily based on empirical data from user tests conducted over a limited period, and on the use of health data for research purposes. Participants who meet the inclusion criteria and not the exclusion criteria will be asked to participate in a longitudinal study and continue with symptom registration in the app. Future research could explore compliance over a longer period and investigate how the mobile app might be integrated into clinical practice and other digital health services to enhance its usefulness.

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Declaration on Generative AI

The author(s) have not employed any Generative AI tools.

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