Archives of Gynecology and Obstetrics (2026) 313:28
https://doi.org/10.1007/s00404-026-08308-3

RESEARCH

# App supporting surveillance for (likely) pathogenic TP53 variant carriers: acceptance among a German cohort

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Received: 22 May 2025 / Accepted: 5 January 2026
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## Abstract

The rapid digitalization of healthcare is transforming medical care strategies. Individuals carrying (likely) pathogenic *TP53* germline variants (P/LP *TP53*) require complex surveillance protocols. To support these individuals, we provided the adapted *PatientConcept* app to adults with a P/LP *TP53* variant and their relatives. We analyzed the value of this adapted app for this cohort, as well as general aspects of Internet use, web-based healthcare options, mental and physical health, and fear of progression. (FOP). From a larger study consisting of 70 carriers and 43 relatives, 25 affected individuals and no relatives installed the app. App users tended to be younger and physically fitter but reported higher levels of psychological distress and FOP compared to non-users. Users rated their distress as high and expressed interest in an on-demand intervention tool offering concise information sessions. Overall, users were satisfied with the app, finding it useful and easy to understand, though they identified areas for improvement. Many app features were underutilized, indicating a need for further adaptation to the target group. Most users obtained medical information online, considering it helpful but often unreliable and difficult to evaluate. Nevertheless, app users felt confident in their ability to use the Internet for health-related search. Our study demonstrates the feasibility and acceptance of an app for individuals with LFS, supporting their surveillance and health behaviors.

**Keywords** Li–Fraumeni syndrome · Cancer prevention · eHealth · Surveillance · Fear of progression

**What does this study add to the clinical work**

This study provides first evidence that a tailored digital health application is both feasible and generally well accepted by individuals with (likely) pathogenic *TP53* germline variants.

## Introduction

Digitalization in healthcare has recently accelerated, profoundly impacting future medical care strategies. Telemedicine consultations are an integrated standard of medical supply. Mobile devices and health apps are now indispensable in daily life. These technologies hold great promise for revolutionizing care structures, particularly in the management of anxiety and depression [1]. The "patient as partner" concept has gained traction, empowering patients as active members of their healthcare teams [2]. Furthermore, patient-reported outcomes (PROs) are increasingly being used to identify patients for targeted interventions to improve care approaches, in particular as electronic PROs (ePROs) [3]. Given limited healthcare resources and the challenges of accessing specialized care in rural and underserved areas, the implementation of digital health solutions, such as digital health applications, is becoming critical. These tools have the potential to enhance accessibility, optimize resource allocation, and improve patient outcomes in diverse settings [4, 5].

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Published online: 10 January 2026

Complex surveillance strategies are recommended for (likely) pathogenic *TP53* germline variant carriers (P/LP *TP53*). The variants cause Li–Fraumeni Syndrome (LFS), a highly aggressive cancer predisposition syndrome (CPS) [6]. To follow the currently recommended surveillance protocol, several medical appointments per year are required (e.g., whole-body, breast, and brain MRIs) [7]. Previous research has shown that these demands create significant organizational challenges to affected individuals and families [8]. To master these challenges and provide relief in the complexity of up to 3 monthly medical appointments, we adapted an app previously described for neurological disease to support self-empowerment among this vulnerable cohort [9]. Additionally, we offered options for PROs regarding distress parameters to warrant future interventional studies based on a need assessment.

This study aims at a) evaluating the technology affinity among individuals with LFS, b) testing the feasibility and acceptance of an app to support individuals with LFS in managing the complex surveillance requirements, and c) deriving implications for the potential of ePROs for patients with CPS.

## Methods

### Study population

For this study, we analyzed the *PatientConcept* app specifically adapted for LFS as well as general aspects of Internet use and web-based options for health care topics. A study questionnaire was offered to people with a (likely) pathogenic *TP53* (P/LP *TP53*) variant aged ≥ 18 years and their relatives. Data were captured between March 2020 and December 2021. As this study is part of a larger study (DRKS00021040), details on our cohort and recruitment are published elsewhere [10, 11]. The study protocol was approved by the local ethics committees (Heidelberg: S-017/2020; Hannover 7233), and written informed consent was provided by all participants.

### Study instruments and statistical analysis

Internet usage and web-based health offers were evaluated with three self-designed questions with options to choose: *Which Internet-enabled devices do you have? How regularly do you use the Internet? Which Internet sources do you use to get health-related information?*

Furthermore, five items of the E-Health Literacy Scale (eHEALS) were applied: *a) I have the skills I need to evaluate the health resources I find on the Internet, b) I can tell high-quality health resources from low-quality health resources on the Internet; c) I feel confident in using information from the Internet to make health decisions (1 = strongly disagree to 5 = strongly agree)* [12]. Furthermore, we assessed how participants perceive the role of the Internet in supporting health decision-making and the significance they attribute to access to online health resources.

For assessing psychosocial variables, we used the National Comprehensive Cancer Network distress thermometer (10 = extreme distress, 0 = no distress) and the fear of progression questionnaire-short form. It includes 12 items evaluated on a 5-point Likert scale (1 = never, 5 = very often), concerning the fear of cancer recurrence and its possible consequences. We replaced "illness" with "LFS" to adapt the questionnaire to our study group. For example, "I am worried that at some point in time I will no longer be able to pursue my hobbies because of LFS". The SF-12 was used to assess health-related quality of life (HRQoL). The questionnaire results in two subscales: a mental and a physical component score. Scores range from 0 to 100, with 100 representing maximum HRQoL. Data from psychological assessments were analyzed for the entire study cohort. This report focuses exclusively on the outcomes observed among app users.

The app included PROs, specifically anxiety and lifestyle assessments. Participants could fill out these as often as they wanted. To determine the change in anxiety over the course of surveillance, reminders were sent via the app at regular intervals, i.e., 3 weeks or 1 day before and after the surveillance. We instructed the participants to regularly complete the PROs, especially around the timepoint of medical appointments. The state trait inventory STAI in a shortened version by Grimm with 10 items was adapted for a mobile device [13, 14]. We used the validated instrument for current anxiety (state) with a scale of 1–4 as described by Ostapczuk for technical implementation on mobile devices [15]. According to previous work, items such as "I am calm" and "I am concerned" are rated on a four-point Likert scale from "not at all" to "very" [16]. The raw response values are summed up to a total state anxiety value. The lifestyle assessment included five short self-designed questions on sleep, nutrition, sports, physical symptoms, and mood inspired by validated questionnaires.

The app could be evaluated at any time from 1 (very good) to 6 (insufficient), and free-text responses were possible. To additionally evaluate the app more systematically, we conducted a short questionnaire via SurveyMonkey among the app users. This survey was conducted in December 2021. It included 25 self-designed questions about what participants liked, disliked, and which future adaptations of the app should be considered. Participants answered on a 7-point Likert scale (I do not agree at all = 1

–to I fully agree = 7) and had the possibility to add free-text comments.

## Missing data

Missing data occurred primarily due to partial completion of app-based questionnaires and incomplete responses to external surveys. An assessment of missingness did not reveal any systematic missing data patterns across outcomes or time points. For each analysis, explicit denominators corresponding to the number of participants with available data are reported. No imputation of missing values was performed; all analyses were conducted using complete-case data for the respective outcomes. Given the exploratory nature of the study, this approach was considered appropriate.

## App technology

The *PatientConcept* app as previously described was adapted for LFS with the option to monitor surveillance [17]. Within this app patients can see seminars, news, opening hours of their doctors' office, they can write to get a prescription or a new appointment. Furthermore, they are offered a diary, pill reminder, notes, messages, and even more functions [9]. Upon registration, participants received a personal code for pseudonymization and access to LFS-specific content and PROs. (Fig. 1: Screenshot of *PatientConcept* app). Participants were able to access all app questionnaires at any time point as often as they wanted. If a questionnaire was answered more than once by the same person, we only included the first set to consider all participants equally.

*PatientConcept* was discontinued on May 1, 2024 and is no longer available for use, but the data are available for interpretation.

# Results

## Study population

Our study cohort consisted of 25 participants with LFS and no relative. They were part of a bigger study group with 70 individuals with LFS and 43 relatives, which has been previously described [10]. One person did not complete the additional questionnaire, leading to an analysis of demographic and psychosocial data of 24 LFS participants. The mean age of study participants was 39 years

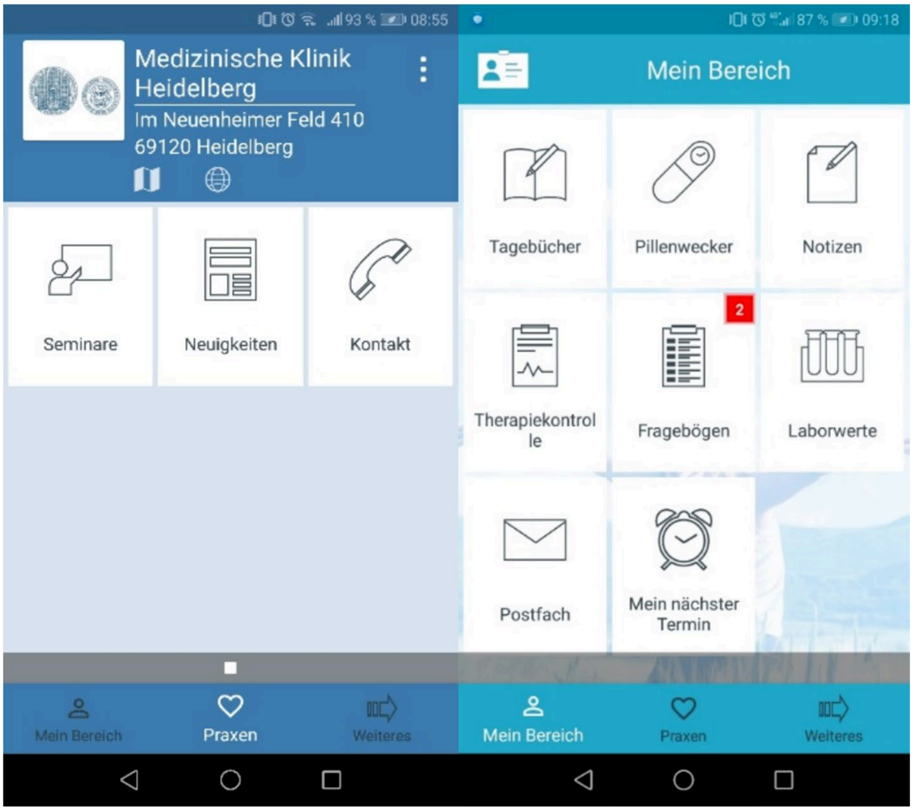

**Fig. 1** Screenshots of PatientConcept App

(SD = 10 years) (range: 22–60 years) and mostly female 83% ($n = 20$). Table 1 shows further demographic characteristics of this study cohort.

The data on psychosocial variables as assessed with the study questionnaire are published for the entire study cohort elsewhere [11]. Here, we present the data for the 24 app users with mean and standard deviation on HRQoL, fear of progression, and distress in Table 2. A cut off of 34 for fear of progression and that of 5 for distress were considered as indicative of needing further attention and perhaps intervention [18, 19].

**Table 1** Study characteristics

| Characteristic | *N* (%) |
|---|---|
| Highest education | |
| Special school certificate | 1 (4.2) |
| Lower secondary certificate | 6 (25.0) |
| Secondary certificate | 1 (4.2) |
| High school certificate | 7 (29.2) |
| University degree | 7 (29.2) |
| Current occupation | |
| Scholar/student | 4 (16.7) |
| Employee | 13 (54.2) |
| Employee (public service) | 4 (16.7) |
| Pensioner | 1 (4.2) |
| Insurance status | |
| State | 21 (87.5) |
| Private | 3 (12.5) |
| Marital status | |
| Single | 4 (16.7) |
| In a relationship | 6 (25.0) |
| Married | 12 (50.0) |
| Divorced/separated | 2 (8.3) |
| Have children | 14 (58.3) |
| Cancer history | |
| Child(ren) with cancer history | 3 (12.5) |
| Own cancer history | 18 (75.0) |
| One or more sibling with LFS diagnosis | 9 (45.0)[1] |
| Surveillance participation | |
| Complete adherence to surveillance | 13 (56.5)[2] |

[1] Number = 20; [2] Number = 23

## Internet use

Data on Internet use were available for 69 individuals of the LFS cohort and for 43 relatives. The LFS cohort includes app users and all other P/LP *TP53* carriers but no relative. The majority of participants reported owning three Internet-enabled devices (app users: 56.5%, LFS: 47.1%, and relatives: 72.1%), mainly computers, tablet, and smartphone. Almost all participants reported that they use the Internet several times a day (app users: 95.7%, LFS: 92.8%, relatives: 95.3%). When asked which Internet sources they use to gain information about health, most of the app users had two kinds of sources (43.5%): search engines ($n = 20$, 87%), Wikipedia ($n = 11$, 48%), or social media ($n = 9$, 39%). Some also mentioned the cancer information homepage by the German Cancer Research Centre ($n = 8$, 34%), scientific databases ($n = 6$, 26), and YouTube ($n = 5$, 22%).

## eHealth literacy

We used five items of the eHEALS questionnaire to assess perceived skills at using information technology for health. When asked about the usefulness of the Internet in making health-related decisions, 5 participants rated it as not useful (at all), whereas 12 rated it as (very) useful. Six participants were unsure. Of the entire LFS cohort, the majority ($n = 26$, 37.7%) was unsure, whereas 17 relatives (39.5%) considered it useful and 13 (30.2%) were unsure. Asking about the importance of access to health resources on the Internet, the majority considered this (very) important (app users: $n = 18$, 78.3%, LFS: $n = 48$, 68.9%, $n = 36$, 83.7%). The mean and SD of the remaining three items (range 1–5) can be found in Table 3.

## Lifestyle

Lifestyle items were the most frequently used app features: 17 individuals completed this questionnaire, with one person doing so on 42 days. The results are displayed in Table 4. Only the most answered options are shown.

**Table 2** Psychosocial sample characteristics of the app users; for the entire study cohort, see [11]

| Variable | *N* | Minimum | Maximum | Mean | SD |
|---|---|---|---|---|---|
| Physical component score | 24 | 33.45 | 64.45 | 51.15 | 9.07 |
| Mental component score | 24 | 24.64 | 57.28 | 39.36 | 9.99 |
| Fear of progression sum score | 24 | 26.00 | 60.00 | 41.58 | 8.60 |
| Distress last week, including today | 24 | 2.00 | 9.00 | 6.17 | 2.14 |

**Table 3** Results of eHealth literacy items, (Min: 1, Max: 5), $^1N=42$

| Item | App users ($N=24$) | SD | LFS cohort ($N=69$) | SD | Relatives ($N=43$) | SD |
|---|---|---|---|---|---|---|
| I have the skills I need to evaluate the health resources I find on the Internet | 3.91 | 1.20 | 3.78 | 1.12 | 3.88 | 1.03 |
| I can tell high-quality health resources from low-quality health resources on the Internet | 4.04 | 1.07 | 3.87 | 1.10 | 3.93 [1] | 1.00 |
| I feel confident in using information from the Internet to make health decisions | 3.96 | 1.15 | 3.64 | 1.18 | 3.63 | 1.02 |

$N$ = Number

**Table 4** Results of the lifestyle questionnaire

| Item | $N$ (%) |
|---|---|
| I ate healthy today | 11 (64.7) |
| I had trouble to fall asleep or sleeping through the night | 6 (35.3) |
| I was not much physically active today | 11 (64.7) |
| Overall, I feel powerless today | 7 (41.2) |
| Overall, I feel burdened today | 8 (47.1) |

$N$=Number

## State anxiety

Information about their state anxiety was given by 8 of 24 participants. The three items with the highest mean were: "*I am worried*" (mean = 3, SD = 0.93), "*I am nervous*" (mean = 2.88, SD = 0.64), and "*I feel tense*" (mean = 2.75, SD = 1.16). Summing all ten items, the mean was 27.28 (SD = 6.57), with a minimum of 17 and a maximum of 39.

## App evaluation

Nine participants provided feedback via the app. Evaluating the app itself, the mean grade was 2.78 (SD = 1.20; $n$ = 9) similar to German school grades, with 1 being the best and 6 being the worst. Answers to free-text questions on desired changes to the app were:

- Clear view of appointments of all family members, including relevant contact information for each appointment
- Improved calendar overview
- Alert to timely schedule an appointment
- Question and answer module.

Of our app users, 13 (25%) opened the separately (via SurveyMonkey) provided evaluation questionnaire. One person only answered the questions on age and gender. The mean age of this sample was 34.85 (SD = 5.5) (range: 28–51 years, $n$ = 13) and 69.23% ($n$ = 9 of 13) were female.

Three of these participants were still using the app (23%). When asked for an overall rating, most considered it "okay" ($n$ = 4, 33%) and it "needs improvement" ($n$ = 3, 25%). All but one person (8%) liked the general idea of an app to coordinate doctors' appointments especially for individuals with LFS. However, 42% ($n$ = 5) considered this app helpful to keep an overview of their appointments. Further items on perceived usability and planned usage are listed in Table 5.

The most frequently suggested future improvements concerned the need for more detailed information, particularly regarding recommended surveillance ($n$ = 10, 83%), general information on LFS ($n$ = 7, 58%), and financial aspects related to living with LFS ($n$ = 8, 67%). Participants also expressed a desire for access to a local contact person ($n$ = 7, 58%) or one based in Germany ($n$ = 5, 42%). Half of the respondents who completed the evaluation questionnaire ($n$ = 6) indicated that having the possibility to communicate directly and schedule appointments through the platform would be beneficial. Furthermore, some participants ($n$ = 5, 42%) wished to be able to check laboratory results and radiology images, similar to the features available in digital patient records.

Participants were also asked to rate the individual app features. The most frequently used functions included the appointment reminder ($n$ = 4, 33%), which half of the participants rated as good ($n$ = 6), the recommended appointment schedule ($n$ = 3, 25%), and the study team questionnaire ($n$ = 3, 25%). The questionnaire function was rated positively by five participants (42%), while one participant (8%) considered it unnecessary. In contrast, several features were seldom used, including the medication reminder ($n$ = 10, 83%), the notes function ($n$ = 11, 93%), the "contact study team" option ($n$ = 8, 67%), and the news section ($n$ = 7, 58%).

Most users ($n$ = 11, 92%) reported a high level of interest in an online program aimed at supporting individuals with LFS in coping with psychosocial challenges, such as fear of disease progression. The key requirements identified for such a program included flexibility in use ($n$ = 7, 58%) and access to comprehensive information ($n$ = 4, 33%), preferably presented in short and easily accessible formats ($n$ = 4, 33%).

**Table 5** Perceived usability and future usage, N = 12

| Future usage | I do not agree at all *N* (%) | I do not agree *N* (%) | I tend to disagree *N* (%) | neither *N* (%) | I tend to agree *N* (%) | I agree *N* (%) | I fully agree *N* (%) |
|---|---|---|---|---|---|---|---|
| I will use this app again | 2 (16.67) | 0 | 2 (16.67) | 2 (16.67) | 2 (16.67) | 3 (25 00) | 1 (8.33) |
| I would recommend this app to my friends and others | 0 | 3 (25.00) | 2 (16.67) | 2 (16.67) | 2 (16.67) | 2 (16.67) | 1 (8.33) |
| Perceived usability | | | | | | | |
| I find the operation of the app easy to understand | 0 | 0 | 1 (8.33) | 1 (8.33) | 2 (16.67) | 6 (50.00) | 2 (16.67) |
| The app is easy to use, even when visiting it for the first time | 0 | 0 | 2 (16.67) | 0 | 4 (33.33) | 5 (41.67) | 1 (8.33) |
| I find it easy to find the information I am looking for | 0 | 0 | 2 (16.67) | 3 (25.00) | 4 (33.33) | 3 (25.00) | 0 |
| I can easily understand the structure of the app | 0 | 0 | 1 (8.33) | 1 (8.33) | 4 (33.33) | 4 (33.33) | 2 (16.67) |
| It is easy to find my way around the app | 0 | 0 | 1 (8.33) | 1 (8.33) | 4 (33.33) | 5 (41.67) | 1 (8.33) |
| The content is organized so that I know where I am at all times | 0 | 0 | 2 (16.67) | 1 (8.33) | 5 (41.67) | 3 (25.00) | 1 (8.33) |
| I can quickly reach information I'm looking for | 0 | 0 | 2 (16.67) | 3 (25.00) | 3 (25.00) | 4 (33.33) | 0 |

*N* = Number

## Discussion

This study aimed to evaluate technology affinity within a cohort of individuals with LFS, assess the feasibility and acceptance of an app designed to support their management of complex surveillance, and derive implications for the potential use of ePROs in individuals with LFS. Individuals who used the app tended to be younger and physically fitter, yet they reported higher levels of psychological distress and fear of progression than the overall study cohort [11]. The age distribution of app users aligns with previous findings indicating that mobile device and health application use is more common among younger individuals, as demonstrated in studies of breast cancer survivors as well as in population-based research in Germany [20, 21].

In this study, an app originally developed for neurological disorders was used and adapted within the available financial and technical resources. This approach enabled this preliminary study as participants expressed satisfaction with the app and perceived it as both, useful and intuitive to navigate. However, for larger cohorts and interventional approaches, the development of a new tailored app would be beneficial, as the previously used app is no longer available. Since the *PatientConcept* app has been unavailable since May 2024, all recommendations regarding functionality refer to a future successor app or comparable digital solutions. Such an app should exclude cohort-irrelevant functions to avoid overcomplexity while ensuring high acceptance and practical applicability. Especially, refinement would be required, with respect to the appointment overview and notification system, which posed challenges for CPS users coordinating more than one person via app. A better design of the contact information section, including the integration of a chat function, as well as the addition of more comprehensive information on surveillance protocols, LFS, and financial aspects related to LFS, should be considered. Despite the range of available features, overall app usage was lower than anticipated. Barriers identified in previous work, including concerns regarding usability, data privacy, technological reliability, and digital literacy, may also have influenced engagement in our cohort [22]. Another contributing factor may be the absence of a strong patient–physician relationship, in this study setting, that has been shown to influence perceived usefulness—an important determinant of digital health intervention uptake [23]. Clear guidance on how and when to use an app may help reduce nonuse and dropout in future implementations with another app [24]. Severe mental health issues are known to be a barrier for the use of digital health interventions, which occurred in our study cohort [25]. In terms of HRQoL, our results align with prior studies. Those indicated that a cancer (predisposition) diagnosis in women with breast cancer is associated with reduced psychological well-being, while physical well-being remains comparable to that of the general population [26, 27]. On average, app users also demonstrated clinically elevated scores of FoP which can reduce quality of life and cause suffering and therefore should be provided access for psychological support. In concordance to FoP, the app users rated their distress quite high indicating a need for psychosocial support [28]. An app-based online intervention designed for LFS could be useful and might limit reservations to an app: Reduced symptom burden via an app has been shown successfully in patients with breast and prostate cancer under therapy [29]. As an example, the MIKA app, a German app designed for cancer patients also demonstrated a reduction in psychological distress after 12 weeks in patients with gynecologic tumors [30].

Most of the app users gain medical information via the Internet, considering it very helpful and important. Mainly search engines deliver extensive information with uncertain reliability and are difficult to evaluate for many people. However, our app user cohort felt skilled and confident to use the Internet properly for health search [31]. Therefore, a new app or homepage providing reliable information could help them to stay informed about their own and other health issues. Regardless of the digital platform used, it is essential that current medical developments are communicated to patients in a clear, reliable, and timely manner. These platforms shall enable patients to access the latest evidence-based knowledge more quickly and effectively. Previous studies have also shown that cancer patients often require support in identifying reliable health information and in navigating online health resources [32]. Therefore, it may be advantageous to use applications specifically designed for CPS, which provide structured, evidence-based, disease-specific content and pre-filter relevant information for users. The information provided should be presented in different forms such as texts and videos to promote vividness but also deeper processing [33].

In contrast to the findings of our preliminary study, which indicated that most participants did not follow a Mediterranean diet but engaged in high levels of physical activity, most app users in the current study reported adhering to a healthy diet while engaging in comparatively little physical exercise [10]. However, evidence suggests that physical activity in breast cancer patients can be effectively promoted and improved through app-based interventions [34]. This finding also points to further potential for utilizing an app to offer targeted lifestyle interventions within such specific cohort. While the majority of participants did not report sleep disturbances or feelings of helplessness and being overburdened, these domains could be monitored via a new app and used to trigger targeted, needs-based interventions.

The state anxiety values in our sample were comparable to those reported in breast cancer patients prior to therapy, highlighting the elevated anxiety among app users and their need to improve mental health. This may be addressed in the subsequent study phase of our project, in which an application specifically designed to provide psychological support will be evaluated [35].

## Limitations

This study is subject to several limitations. First, the sample size was small, which limits the generalizability of the findings. Second, a follow-up evaluation of the app could not be conducted, as the platform has since been discontinued by the provider. The subsequent discontinuation of the *Patient-Concept* app by its developer (NeuroSys) as of May 2024 may have several reasons. One contributing factor may have been the relatively limited use and perceived benefit among individuals with LFS. Additionally, the continuous development, maintenance, and updating of a digital application is resource-intensive and associated with ongoing costs. Given the minimal funding available, these factors likely contributed to the decision not to continue the app's further development. This may restrict the long-term applicability and clinical transferability of the findings. Therefore, our findings should be interpreted as guidance for the future development and implementation of digital health solutions. This experience underscores the need to balance regulatory, economic, and user-related considerations when planning future digital health applications.

Nonetheless, the insights derived from this study provide valuable guidance for the development and evaluation of future digital health applications with comparable objectives and functionalities.

## Outlook

In future, particularly larger scale studies, subsequent work should focus on developing a new customized successor application that builds upon the insights gained from this project. Functions that were rarely or not utilized in our app, which is no longer available, may be omitted, whereas features identified by participants as particularly useful should be retained or further enhanced. A user-centered and needs-oriented design may improve both the acceptability and usability of future digital tools for individuals with CPS, thereby promoting sustained engagement and supporting their clinical applicability.

For the design of future online support interventions for individuals with LFS, it is particularly relevant that the majority of participants indicated a preference for a flexible, on-demand tool offering brief, easily digestible informational sessions.

**Author contributions** JN: Data collection and analysis, Manuscript writing SK: Data management and analysis, Manuscript editing FS: Manuscript editing MK: Manuscript editing CPK: Manuscript editing IM: Project development, Manuscript editing SS: Project development, data collection, manuscript writing.

**Funding** JN was supported by the Faculty of Medicine Heidelberg in the form of the Rahel-Goitein-Strauss fellowship. SS has been supported by the Bundesministerium für Bildung und Forschung, Federal Ministry of education and research, BMBF (01GM1909D), CPK by Bundesministerium für Bildung und Forschung, Federal Ministry of education and research, BMBF (01GM1909A). CPK has been supported by the German Childhood Cancer Foundation, Deutsche Kinderkrebsstiftung (DKS2019.13). IM has been supported by the Bundesministerium für Bildung und Forschung, Federal Ministry of Education and Research, BMBF (01GM1909D).

**Data availability** The data that support the findings of this study are not openly available due to reasons of sensitivity and are available from the corresponding author upon reasonable request.

## Declarations

**Conflict of interest** The authors declare no competing interests.

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