Long COVID Diary: A User Centered Approach for the Design of a Mobile Application Supporting Long COVID Patients

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Abstract: A significant part of patients who have recovered from COVID-19 has been experiencing COVID-like symptoms for weeks and months after the initial disease. These patients have been called “Long COVID patients”. Currently, guidelines are being published that inform about these symptoms and may deliver a basis for medical diagnoses. In this paper, the possibility of a Long COVID patient support app is being discussed. To gain insight into the needs and requirements of patients with Long COVID, a questionnaire was conducted with 193 participants from a self help-group in Austria. The results show that Long COVID has a profound negative impact on the daily lives of people who are suffering from the disease. Also, the results show a demand for more support and indicate the role that a Long COVID symptom tracking app could play in this context. Concerning digital support, ten crucial features of a potential Long COVID support app were identified by analyzing the answers to the questionnaire. Apart from health and symptom tracking features, sharing of data with medical professionals, appointment management, and news features were considered important features to support patients suffering from Long COVID throughout their journey to get better.

1 INTRODUCTION

Since the beginning of 2020, the COVID-19 pandemic has fundamentally impacted and changed many aspects of our society. Due to the disease’s high contagiousness, many countries have engaged in repeated lockdown periods and tried to enforce social distancing. Despite these efforts, millions of people worldwide and hundreds of thousands of people in Austria have contracted COVID-19. While many of these patients have recovered fully, a significant portion suffers from COVID-19 symptoms long after they were declared as cured. As of November 2021, over 1 million people in Austria have contracted COVID-19, while over 12 000 people have died from the disease. Globally, there are 258 million recorded cases of COVID-19, and over 5 million deaths (Dong, Ensheng and Du, Hongru and Gardner, Lauren, 2020).

The persistence of COVID-19 symptoms after the patients have recovered from COVID-19 is commonly referred to as *Long COVID*. These symptoms include (among others) fatigue, shortness of breath, chest pain, memory and concentration problems, and dizziness (Venkatesan, Priya, 2021). Determining the incidence of Long COVID is difficult, since currently there exists no single definition with international recognition. Despite this, some studies assume that around 10% of COVID-19 patients develop Long COVID symptoms after recovering from COVID-19 (Mahase, Elisabeth, 2020).

Independent of how the COVID-19 pandemic progresses internationally, the problem of Long COVID is getting more and more relevant and still has many unknown factors. One drawback people with long covid experience is often sharp declines in their qualities of life, and their inability to perform daily tasks reliably (Nabavi, Nikki, 2020).

Unrelated to COVID, a trend among healthcare professionals and researchers has emerged to combine all relevant data generated over a patient’s treatment for a disease. This concept of mapping data onto a *Patient Journey*, and therefore combining various inputs and data points from multiple healthcare providers and patients has become increasingly important over the last years (Georghiou, 2021). The Patient Journey model has primarily been used within healthcare facilities to provide their patients with information and prevent the impact of conflicting or outdated information. For instance, services to improve the Patient Journey are used with peri-operative patients (Willems, Stijn J and Coppieters, Michel W and Pronk, Yvette and Diks, Miranda JF and van der Hei-

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jden, Klaas WAP and Rooker, Servan and Scholten-Peeters, Gwendolyne GM, 2021) or with stroke patients (Davoody, Nadia and Koch, Sabine and Krakau, Ingvar and Hägglund, Maria, 2016).

Patient Journey apps are applications that provide their users with information about their illness and their treatment. These apps may allow users to track their health progress and keep in touch with healthcare providers. In general, Patient Journey apps are designed for calls to action at relevant points of time and accompany them on their “health journey”, besides being a central information point regarding their situation. Ideally, a Patient Journey app’s first goal is to support patients at all times, not just when interfacing with medical professionals (Timmers, Thomas and Janssen, Loes and Kool, Rudolf B and Kremer, Jan AM, 2020).

The emergence of personal computer devices with health data recording capabilities (e.g., smartwatches, phones, fitness tracking wristbands) has opened new ways of generating, interpreting, and collecting health data. Major phone companies, such as Apple (Apple, 2021), Google (Google, 2021), and Samsung (Samsung, 2021), provide first-party applications, which aim to be a central and secure storage for all kinds of personal health data. Modern Patient Journey applications are expected to integrate with the patients’ phones, and as a result, can use a plethora of useful health data. The data that is recorded using users’ phones may not be reliable enough to support medical decisions (and few, if any, widely available health devices are classified as medical devices), but the sheer amount of acceptable health data recordings might provide benefits for the patients and their medical supporters nonetheless (Klasnja, Predrag and Pratt, Wanda, 2012).

Due to the relative uncertainty among researchers and medical professionals, the risk of misdiagnosis for patients with Long COVID is large. Since many of the symptoms of Long COVID have a cognitive aspect (e.g., fatigue or diminished concentration), some patients have been diagnosed with depression or other psychological disorders (Nabavi, Nikki, 2020). In the authors’ opinion, a Long COVID app should ideally help patients record their daily symptoms, and therefore support them in managing their illnesses.

Additionally, a Long COVID app should be able to record reliable data, which should be helpful to doctors and other healthcare professionals.

From a more broad perspective, using the ubiquity of smartphones to provide patients of Long COVID with a support app seems patently worthwhile. In addition to supporting patients by letting them track their symptoms and receive useful information, such an app could also aid medical treatment, e.g., by having an option to share patient data.

As knowledge of the disease itself is still developing, and medical guidelines are currently being published, the risk of misdiagnosis is ever-present (Raveendran, 2021). One possible solution is enabling the patients to systematically record their daily health and create a reliable basis of data. Using this data, the quality of medical decisions may be improved.

This paper covers a user centered approach for the requirements analysis of a Long COVID Patient Journey App (the ”Long COVID Diary”) and the proposal of expected features. As the amount of available research for Long COVID is still comparatively small, an exploratory approach to requirements analysis has been taken, as this information is currently missing from state-of-the-art research. To that end, a specific questionnaire was created to gather information on what a possible Long COVID support app should do.

The following sections are structured as follows: Section 3 contains related work, section 2 describes the methodology that was used to gather feedback from long COVID patients as well as their corresponding requirements, which are outlined in section 4. This publication concludes with a discussion and possible future work in section 5.

2 METHODOLOGY

Tho get to know the current state of long COVID patients and requirements for a supporting app a questionnaire was conducted in German using Google Forms together with a public participation link. The questionnaire was conducted among *Long COVID Austria*, an Austrian self-help group for patients suffering of Long COVID (Long COVID Austria, 2021). An English version of the questionnaire can be provided by the authors on request.

The questionnaire is divided into four sections, with the first section being an introductory text to inform the participants of the aim and setting. The second section, *Health Questionnaire* (in German: *Gesundheits-Fragebogen*) contains translated items from the CHSS’ *Living With Long COVID* questionnaire (CHSS - Chest Heart & Stroke Scotland, 2021). The third section contains questions and research items about potential app features and the participant’s general technical ability. Finally, in the fourth section, relevant demographic items are included.

The questionnaire was conducted over five weeks via Google Forms. After the initial contact with a group administrator, the link for participating in the study was shared among members of said group (e.g., in a private Facebook group). Until the end of the conduction period, no further contact was made with the participants, nor was access to the Facebook group granted to the researcher. The influx of results was monitored sporadically, and no systematic trends regarding the participation frequency were observed. After getting back the results, they were analyzed and discussed for preparing a possible future implementation of the app based on the needs of long COVID patients.

3 STATE OF THE ART

In current state-of-the-art solutions, no similar application covering Long COVID aspects was found. In particular, no app publicly in development or available aims to offer health diary functionality to patients. Instead, most COVID-related apps that were identified, put their focus on patients with COVID-19, rather than patients with Long COVID.

Collado-Borrell et al. (Collado-Borrell et al., 2020) identified 114 apps related to COVID-19. 62 (54,4%) were developed for Android, 52 (45,6%) for iOS, and 50 (43,9%) for both operating systems. Most of these apps were developed in Europe, followed by Asia and North America. The most used languages are English, Spanish and Chinese. Most of these apps were developed in the name of governments or companies related to the health sector. In addition to these findings, Ramakrishnan et al., (Ramakrishnan et al., 2020) also published similar findings.

Perhaps most prominently, a research app co-created by researchers from the University of Leeds is currently being used by 27 hospitals in the UK (University of Leeds, 2021). This app uses the Yorkshire Rehabilitation Scale to track individual health progressions (Sivan et al., 2021).

When looking at the broader field of healthcare, several state-of-the-art projects that aim to offer health diary functionality become apparent. For mental health diary apps, several key traits for successful app development were identified by Goodwin et al. (Goodwin et al., 2016). The researchers identified readily available information, easily usable diary features, and graphic representation of results as the most requested features among their sample. In a study by Yoo and Suh (Yoo and Suh, 2021), a self-care health diary app for recipients of a heart transplant was developed, and tested among a small number of patients. The patients who participated in this study responded highly positive to the app, but reported the wish for better usability. In a literature overview by Lee et al. (Lee et al., 2018), a sizable number of mobile healthcare apps (including both medical and non-medical applications) were compared. The researchers state that while many of these apps could show success within their study, few apps would then be further developed.

4 RESULTS

The questionnaire - given to a group of patients of Long COVID (who would later be the main target group for a Long COVID app) - should both provide insight into the needs of this patient group as well as specific requirements for and identification of relevant app features. Furthermore, conducting this exploratory survey among patients of Long COVID should deliver valuable insights into whether a Long COVID-related app is desired by its most likely target group and could support their recovery.

The questionnaire contains both a medical as well as an app-related section. The medical section provides insight into how patients with Long COVID deal with the illness and its symptoms on a day-to-day basis. The app-related section is used to gauge interest in suggested features, as well as for allowing participants to suggest app features themselves. Additionally, this section should give a broad overview of the technical abilities of the target group.

The questionnaire was written and conducted in German, and constructed using Google Forms. It is comprised of four sections:

1. **Health:** General questions about the participants' health and impact of Long COVID on their daily lives.
2. **Feature Suggestion:** Items about which features a Long COVID support app should implement in order to be useful.
3. **Technical Skill:** Items that aim to assess the technical ability and willingness to regularly use a smartphone app.
4. **Demographics:** Items about age and gender of participants.

The questionnaire mainly uses choice items, with an option to add a freeform answer wherever sensible. Before starting, the participants were briefed about the goals and length of the questionnaire. The link was shared among participants in their (private) Facebook group.

Overall, 193 participants took part of the study. Rudimentary statistical checks did not indicate any reason to exclude a participant. Therefore, the questionnaire was concluded with an n=193 participants sample. As mentioned earlier, the questionnaire was conducted solely with members of *Long COVID Austria*. The sample is majority female, with 86% of participants identifying as women. The majority of participants are between 25 and 55 years old, with 80% stating their age within this range. While more women than men are assumed to suffer from Long COVID (Daniel Ayoubkhani , 2021), the sample likely skews more female than the general population of patients with Long COVID. The sample also likely skews younger than the general population since *Long COVID Austria* is primarily organized online.

4.1 Symptoms of Long COVID

In the sample, approximately 77% of participants have been suffering from Long COVID for longer than four months, with another 19% suffering for two to four months.

The most common symptoms experienced are (in decreasing order of frequency): Fatigue, lack of focus or brain fog, tachycardia, headaches, and difficulties breathing. Other symptoms include loss of sense of smell or taste and various physiological and psychological symptoms.

Close to 90% of participants reported fatigue, and 79% of participants reported lack of focus as a symptom. These two symptoms are by far the most common among the sample. Notably, around 11% of participants reported a loss of sense of taste, which is a salient symptom of COVID-19.

Self-reported symptoms were manifold and included reports of debilitating weakness, insomnia, and gastrointestinal distress. These symptoms were clustered into either “physiological” or “psychological” to allow better representation. For more information, see Figure 1.

Most participants report daily fluctuation in their perception of symptoms, with 64% stating that their symptoms varied “day to day”.

The impact of COVID-19 and Long COVID on the perceived health of the participants is significant: 97% of the participates indicated that they believe, before getting sick with COVID-19, the state of their health seemed as either *Very Good* or *Good*. After the disease, and while dealing with Long COVID, almost as many (93%) report that their health has declined. More notably, every participant noted a deterioration in their health (by reporting a better state for Item 4 than for Item 5). See Figure 2 for more information and the appendix for the exact phrasing used for both items. Well above 80% of participants report that the disease has impacted their social life, work life, and mental health negatively. More than 60% state that their relationships have been affected by Long COVID. For more information, see Figure 4.

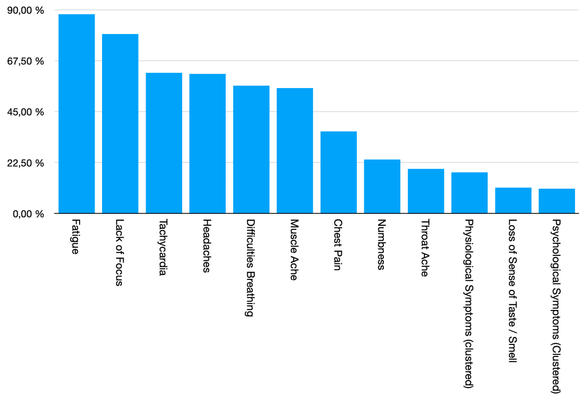

Figure 1: Reported Symptoms (Multiple Choice + Freeform Entry).

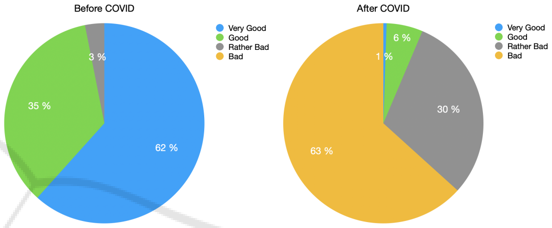

Figure 2: Reported State of Health Before (left) and After COVID-19 (right).

4.2 App Features & Technical Ability

Overall, the sample has shown a high level of self-reported tech literacy. Over 80% of participants state that they mostly or fully agree with the statement “I am competent with technology, and am knowledgeable regarding my phone”. Over 85% of participants report that they use between two and ten different mobile applications every day. Participants were asked which potential features they would deem “important” for a Long COVID support app. An up-to-date overview of support offers for patients with Long COVID was chosen by about 87% of participants. Entering data of various symptoms associated with Long COVID was chosen the second-most often: Entry of fatigue was the most common among this subset, with 80% of participants choosing this answer. The following symptoms were chosen less often: Daily health at 75%, breathing performance at 52%, and blood oxygenation at 50%. The feature of an overview of appointments and events was also chosen quite often (66% for user-defined appointments and 55% for external events). For more information, see Fig. 3.

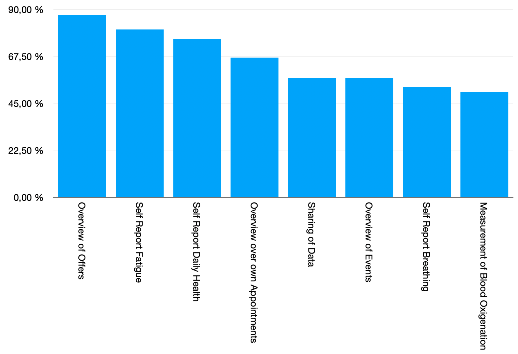

Figure 3: Potential features that were deemed important.

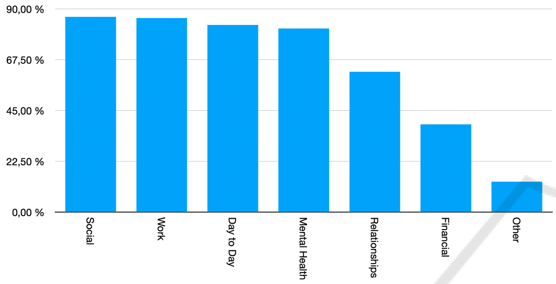

Figure 4: Reported Impact of Long COVID in Different Areas of Life.

4.3 Requirements

Due to its sample size and straightforwardness, the questionnaire results provide a rich basis for informed decision-making in regard to application prototype design. All participants' reported deterioration of personal health is a strong signal to the public to take health care for patients with Long COVID seriously. Furthermore, it signals the need for an app to accompany patients when dealing with the illness. Also, since the majority of participants report that their symptoms vary over time, keeping track of these symptoms is likely to be important as well. The participants all report a high level of interest in a proposed Long COVID mobile application. It stands to reason that the self-reported level of interest is not directly applicable to the expected usage of the app. However, a general level of interest further indicates the need for such an app.

All in all, the findings justify the further planning and development of a Long COVID Support app, the ”Long Covid Diary”. When looking at the results of the questionnaire, some general insights for the development of the app prototype can be gained:

- Many participants have a high demand for an app that lets them track their symptoms.
- The participants in the sample state their motivation for regular use
- Due to the prevalence of neurological and psychosomatic symptoms (e.g., fatigue, lack of focus, etc.), the app has to rely on the users self-reporting their daily state. In the authors' opinions, there is no easily measurable metric available.

Based on these results, a set of app features and requirements have been compiled, which are described in more detail within the following table (see 1). The table provides the feature ID (abbreviated with FE), the feature name, its description, as well as a link to the results of the questionnaire and their justifications to include it in the list.

Features FE02, FE03, and FE04 were mentioned overwhelmingly often in the questionnaire items about app features, whereas in FE01, the entry of blood oxygen values was chosen less frequently than the other features (about 50%). However, several health organizations recommend the continued monitoring of blood oxygen levels using pulse oximeters (e.g., (Healthwise Staff, 2020)). More recently, the use of pulse oximeters by patients without medical supervision has been criticized (Greenhalgh et al., 2021). Despite this, the feature should be included in a prototype in the authors' opinion to enhance the self-monitored symptoms with data collection from sensors.

Feature FE02, the input of data to track symptoms regularly, was mentioned by around 80% of participants. Since many of the symptoms experienced by people with Long COVID are neurological and psychological, direct measurement is often hard or impossible. Therefore, the app should rely on self-report-style questionnaires. Ideally, these questionnaires should be clinically tested, usable and easy to fill in a short period.

Feature FE03, an overview of COVID-related appointments, has no direct impact on health data recording. However, its inclusion is warranted, as the feature's usefulness may increase the frequency and duration of app usage and, therefore, increase the motivation for recording health data.

Similarly, Feature FE04, which was mentioned the most often in the questionnaire (at about 87%), has no direct impact on health data recording but of course on the support of patients of this new disease. Also, being presented with up-to-date news may again increase the frequency of app usage. Feature FE05, a dashboard, is included not for its own sake but as a tool to convey information to the user quickly. A mix of information and prompts to participate are included in the dashboard, which should be the first view presented to the user. Daily questionnaires, such as a daily fatigue questionnaire, could be shown prominently on the dashboard. Also, statistics about symp-

Table 1: Requirements.

ID	Feature Name	Description	Link to questionnaire
FE01	Reading and entering blood oxygen values	This will allow users the entry of blood oxygen values. Blood oxygenation is used as a measure of pulmonary health and is recommended by several health organizations.	The feature was mentioned by about 50% of participants in the questionnaire. Blood oxygenation is assumed to be a valuable metric of pulmonary health.
FE02	Reading and entering questionnaires about Long COVID symptoms	This will allow the entry of various health symptoms using short questionnaires. The questionnaires will be partly based on clinical questionnaires and include freeform items to track diverse symptoms.	The feature was mentioned by about 80% of participants in the questionnaire.
FE03	Reading and entering appointments related to Long COVID	The app will allow the entry and display of Long COVID-related appointments and activities. Integration with the system calendar is also possible. Users may enter appointments using an in-app form and save these appointments in their phones' calendars.	The feature was mentioned by about 70% of participants in the questionnaire.
FE04	Presentation of current news related to Long COVID	This feature will include an overview of recent news gathered by various sources. The app will preview a portion of the news items. After that, a web link to the news source will be given.	The feature was mentioned by almost 90% of participants in the questionnaire.
FE05	A *dashboard*-type feature to serve as a general overview	The dashboard will be the main view on opening the app by default. Here, an overview of current status and activities will be displayed.	While not mentioned explicitly in the questionnaire results, an overview of current activities is a good app design practice based on the authors' opinions.
FE06	Food intake tracking	Tracking eaten meals throughout a more extended period appears to be an obvious feature for a Long COVID support app. The addition of a simple food intake tracking feature allows for a multifaceted view of the users' health.	Food tracking functionality was mentioned sporadically as a free-form answer.
FE07	Entry of other biometric data: Pulse, blood pressure, etc.	Similarly to FE06, the addition of other health-related data (some of which are readily available using fitness tracking devices, e.g., a smartwatch with an integrated pulse meter) may allow for a more broad picture of users' daily health.	The tracking of biometric data, as well as general fitness and movement data was suggested in the free-form answer fields of the questionnaire.
FE08	Entry of physiologic and psychological symptoms	The entry of various symptoms, such as headaches, shortness of breath, panic episodes, mainly using quick questionnaires may benefit the understanding of disease progression for both the users and potentially researchers.	Several symptom tracking features were suggested in the free-form answer fields of the questionnaire.
FE09	Contact data of doctors and medical professionals	As a Long COVID support app becomes important in users' lives, a way to quickly call or message their healthcare providers appears to be a good fit for the app.	The ability to contact healthcare providers was mentioned in the context of FE04. Patients expect to be able to contact their doctors and/or caretakers.
FE10	Share data	The ability to share data is an important feature to connect the data collected by patients with medical workers.	The ability to share data, both with healthcare professionals as well as other people was suggested by the majority of participants.

tom data from the recent past should help users to gain awareness and oversight about their symptoms. Features FE06-FE10 were mentioned somewhat less but were added after internal discussion and comparison with other apps to round off the feature set.

To the authors' opinions, the features described here are important, because they allow the tracking and displaying of health data. Since most participants stated that they would be willing to share the data gathered by a Long COVID support app in some form, the secure storage and export of said data appear to be equally important. Therefore, the inclusion of a feature set to export the data in a generally readable data format (e.g., PDF or CSV) is pursued.

For an overview of the the identified features, see Table 1. The feature-list refers to the results of the questionnaire, which were clustered and condensed.

5 CONCLUSION AND OUTLOOK

The conduction and analysis of the questionnaire has provided useful information and insight into a group of patients whose impact on the health system will only increase in the coming months. At the time of writing, no clear outlook for patients with Long COVID is available. Diagnoses and treatment options are likely to shift and be subject to discussion.

In this context, the development of a mobile application that accurately collects health data is strongly recommended. The app should be reliable in its data collection to provide information not only for the patients but also for medical professionals. Furthermore, a Long COVID app could become a valuable tool for people monitoring their symptoms. As mentioned in previous sections, diagnosing Long COVID is still difficult, and misdiagnoses are a burden for patients and a problem for healthcare systems. Giving patients the ability to track their symptoms regularly might make a difference in improving diagnostic accuracy and, therefore, treating Long COVID.

When looking at the features that were deemed important, it becomes clear, that a successful Long COVID support app should do more than simply track users' symptoms and daily health status. Participants who participated in the presented questionnaire appear to request features that provide up-to-date information, appointments, and activities. Supporting people with Long COVID means more than simply monitoring their health but also assisting them in their daily lives in various ways.

The inclusion and participation of users from the first step in the design and development process is necessary to support the above mentioned goals. Apart from strictly feature-based deliberations, implementing an app prototype should also focus on straightforward, modern design and ease of use principles. Ideally, a Long COVID support app should conform to the platform's UI guidelines whenever possible. The user centered approach in all development stages increases the usability and, again, may increase the frequency of use of the app.

While providing valuable insight regarding the design of an app prototype, the questionnaire and its result are limited by its methodology. One obvious criticism is the selection of the sample and the lack of control of participant access. All participants were members of the *Long COVID Austria* Facebook group. Based on this, the base level of personal interest in dealing with Long COVID can be assumed to be higher than in the general population (of people dealing with Long COVID). This might impact the results of the technical portion of the questionnaire, in which features and expected app usage were stated. But precisely because of the app being specifically designed for Long COVID patients, this user group is the main target of future users.

After initial design, a prototype should be handed out to get further feedback on the implementation of the proposed requirements for a Long COVID application.

In terms of future work apart from the implementation a larger scale evaluation should be conducted afterwards. Within that setting also gamification (motivational) aspects could be covered as well, to see if those elements support the motivation and use of the application by long COVID patients.

The questionnaire and results presented in this paper are the first important step towards developing a Long COVID support app, tentatively named *Long COVID Diary*. The authors think, based on the given results, that such an application is absolutely necessary and should be developed based on the here presented findings. The here presented research provides valuable insight into the requirements of patients with Long COVID and are considered a good starting point for further research and development. Design approaches will be discussed to provide and test the proposed feature-set with the user group following the user-centered design approach.

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