Android App for Symptomatic Monitoring of Cervical Dystonia: Design and Usability Study

Roland Stenger[1,*][a], Rica Schulze[1,*], Sebastian Löns[2], Tobias Bäumer[2] and Sebastian Fudickar[1][b]
[1]*MOVE Junior Research Group, Institute of Medical Informatics, University of Lübeck, 23562 Lübeck, Germany*
[2]*Institute for Systems Motor Science, CBBM, University of Lübeck, 23562 Lübeck, Germany*

Keywords: Smartphone App, Cervical Dystonia, Telemedicine, Asynchronous Video Recording.

Abstract: Movement disorders are characterized by paucity or excess of movement. Access to specialists is difficult for patients living in rural areas, making regular visits for symptom monitoring inconvenient. Asynchronous video recording represents a telemedicine approach with temporal freedom but holds the challenge that clinicians and patients can't interact with each other and thus can't correct errors, which can lead to a decrease in data quality. This article presents an android application (Move2Screen) that aims to enable asynchronous therapy monitoring and addresses the problem of missing interaction by an implemented video protocol for guided recording to capture visible symptoms in the example of cervical dystonia. The videos can be accessed by clinicians subsequent to an automated upload. A user study of the app was conducted, indicating a strong interest and acceptance rate with a high willingness to use the app. Furthermore, the app can be used to record a standardized data set, which allows a large number of patients to be reached without great effort by clinicians and also provides the possibility of a semi-automated video-based analysis of current symptoms and the longitudinal symptom progression.

1 INTRODUCTION

Movement disorders are a group of neurological disorders, that present with involuntary movements. They are caused by a variety of diseases, such as Parkinson disease, Tourette syndrome, Huntington's disease, or dystonia. A distinction is made between hypokinetic and hyperkinetic movement disorders. Hypokinetic movement disorders such as Parkinson's disease are associated with a paucity of movement, whereas hyperkinetic movement disorders such as dystonia are marked by an excess of movement.

This article presents an app for therapy monitoring through the example of cervical dystonia (the most common form of dystonia). Dystonia is characterized by abnormal, sustained muscle contractions that result in twisting or contorting of one or multiple joints. It can manifest in different body areas, such as the neck (cervical dystonia), eyelids (blepharospasm) or the larynx (spasmodic dysphonia as a type of focal dystonia). Dystonia can be classified into focal, segmental, with tremor or generalized forms. For example, "writer's cramp" is focal hand dystonia, while segmental dystonia involves two or more continuous body regions. Generalized or multifocal dystonia impacts multiple body parts simultaneously (Gerpen, 2013).

Cervical dystonia is usually diagnosed and treated by specialists. However, access can be difficult and costly, due to the limited number of movement disorder specialists, movement limitations, underserved areas, and long travel distances (Ben-Pazi et al., 2018)(Srinivasan et al., 2020). However, it is important to monitor the progress of therapy regularly, as the severity of cervical dystonia may change over time and/or as a result of therapy. Cervical dystonia is often treated with botulinum toxin injections, where it is common to receive such injections approximately every 12 to 16 weeks (Ospina Medical, 2023). Continuous monitoring has potential benefits because the effects of the injection vary from patient to patient and side effects that may be caused by high doses can be detected and corrected on an individual basis.

Telemedicine interventions such as (synchronous)

[a] https://orcid.org/0000-0002-7590-7286
[b] https://orcid.org/0000-0002-3553-5131
[*] Authors contributed equally

Stenger, R., Schulze, R., Löns, S., Bäumer, T. and Fudickar, S.
Android App for Symptomatic Monitoring of Cervical Dystonia: Design and Usability Study.
DOI: 10.5220/0012465300003657

In *Proceedings of the 17th International Joint Conference on Biomedical Engineering Systems and Technologies (BIOSTEC 2024) - Volume 2*, pages 201-207
ISBN: 978-989-758-688-0; ISSN: 2184-4305

videoconferencing, which are already being increasingly used (Ben-Pazi et al., 2018), may be able to address these problems. It was found by (Hassan et al., 2018) that 50% of Movement Disorder Society members, mostly physicians, from 83 countries around the world already use and plan to continue using telemedicine interventions such as videoconferencing and video education in the context of movement disorders. In addition, (Ben-Pazi et al., 2018) has shown that Parkinson's patients are satisfied with a video consultation or even prefer it to a face-to-face consultation. A study of telemedicine visits for dystonia came to the same conclusions (Fraint et al., 2020). Another study used web-based videoconferencing to administer the MoCA test to subjects with Parkinson's and Huntington's disease and concluded that administration was feasible with only minor technically related problems (Abdolahi et al., 2014).

While (Ben-Pazi et al., 2018) sees synchronous videoconferencing as an improvement, (Srinivasan et al., 2020) points out that asynchronous methods can overcome the problems of poor internet connections, low resolution, and possible time management problems due to the need for scheduling. In addition, asynchronous methods are suitable for a longer-term exchange, because patient and doctor do not have to make an appointment every time and are more flexible in their time management.

However, telemedicine via asynchronous videos also holds challenges. Information gain is not as good with asynchronous video because clinician and patient can not interact. (Srinivasan et al., 2020) sees the problem that, some features in dystonic disorders can only be detected through task-specific and in site-specific situations. Furthermore, the article emphasizes that the quality of telemedicine analysis may depend on the correct camera angle and good lighting.

This article presents the Move2Screen app, which aims to overcome such problems in the example of cervical dystonia. The app allows patients to record guided videos at home. In these videos, they perform specific movements following a protocol, designed to enhance the detection and assessment of dystonia-specific symptoms. Guided positioning in front of the camera and movement instructions are displayed through an avatar, who imitates the desired movements. The application is asynchronous, so the patient can record videos at any time, overcoming the need for a face-to-face appointment. The integrating of a video protocol that guides the patient through the recording process, is intended to overcome the challenges that arise from the lack of interaction in asynchronous recordings. The video protocol ensures that patients perform standardized movements so that the clinician can identify and assess symptoms and compare multiple videos at the same time stamps. In addition, the app allows patients to complete a questionnaire about their general well-being. This should provide the clinician with information about the patient's condition and the effect of the therapy.

Following, the app is introduced in detail. First, in Section 2.1 the requirements of the app are discussed. Then, the framework of the app is presented in Section 2.2. While the app is still a research prototype, we present the results of a first user study in Section 3.

2 MATERIAL AND METHODS

2.1 Requirements of the App

Having previously discussed the advantages and disadvantages of telemedicine methods, we now want to discuss the requirements for the app. Given the user group that is to use the app and the sensitivity of the data, we identify two particularly important requirements that the app must fulfill.

Ease of Use: As an asynchronous method, user-friendliness is particularly important from the user's point of view, as it is not possible to respond quickly and individually to problems and ambiguities when using the app. Smartphone use is increasing in all age groups. Cervical dystonia often starts between 30 and 50 years of age, whereas dystonia in cranial regions first appears in the fifth or sixth decade of life (Martino et al., 2012). Especially for this reason, it is important to make the app as simple and intuitive as possible, so that users who have little knowledge of smartphones can utilize the app without any problems. Through the user experience study, we are able to evaluate the simplicity of the app, which is discussed in section 3. Another related aspect regarding ease of use is satisfaction, which is also addressed in the usability study. According to (Liew et al., 2019) is this based on their study the most important aspect of health and wellness mobile apps.

Data Protection/Privacy: Person-identifying video recordings can be considered very sensitive data, especially when the aim is to record a visible disease. To prevent discomfort that might come from uncertainty about how the data is processed and its location, it is important to maintain transparency. Regarding the importance of data security, (McGraw and Mandl, 2021) emphasizes that depending on health-related data is used can yield positive or negative effects for both individuals and entire populations. Unauthorized

access could lead to embarrassment and discrimination. Furthermore, the article mentions transparency as an important point to encourage people to provide personal medical data. Before each upload to a server for clinicians to view, users should always know which data has been uploaded and retain full control over the uploading process. We expect that the app will be more widely accepted if users can delete the data as quickly and easily as possible if they wish to do so and the data is taken with care. Therefore, we encrypt all data before it is uploaded. The data is stored on a password-protected server that can only be accessed by medical professionals or those who have the login password and private key to decrypt the data. The study showed that the respondents were least likely to agree with the statement that they don't mind using the app in social settings compared to all other responses. This emphasizes our point about the importance of data security.

2.2 The Framework of the App

In the following, the features of the app are introduced.

General Aspects: The framework is developed with *Android Studio* and is designed for smartphones with Android 8.0 or higher. It uses standardized functional graphical units and will be familiar to Android users, which increases intuitive usage.

Login: On the first start, the user logs in with a QR code, which encodes an individual user ID. The ID is then later used to pseudonymize the data.

Main Page: The app implements a bottom navigation with two tiles, one for video recording, and the other one for the questionnaire, as shown in Figure 1. Both pages have a main button, which starts the video recording process or the questionnaire. A bordered window shows the date of the last data recording and the date of the next planned recording. For fine-scale data collection, we consider weekly collection as a good compromise between adequacy and collection frequency.

In order to give the user the knowledge of which data is already recorded and if it is uploaded (considering the data protection requirement mentioned above), the app provides on both pages, the video recording- and questionnaire- page navigation towards a history page, which list all video recordings or questionnaires respectively. The user can delete the data and see which data is already uploaded. If it is already uploaded, only the local file will be deleted to save storage space. On the same history page, the user

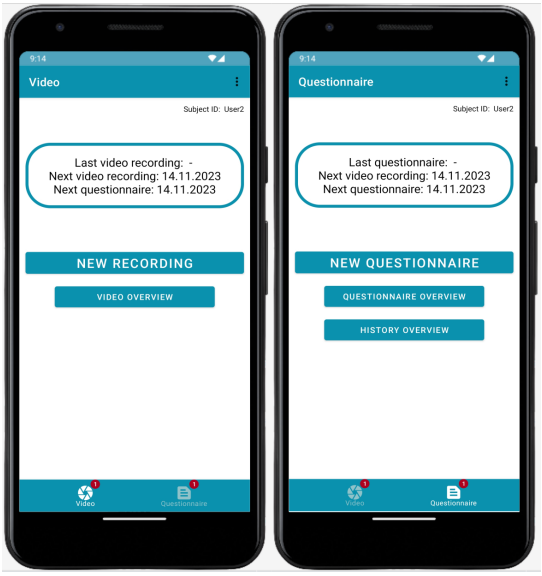

Figure 1: Screenshots of the main pages of the app. The video recording page is on the left side and the questionnaire page is on the right.

is able to watch the recorded videos or all given answers to the questionnaires. Both pages are directly accessible through the main page, as visible in Figure 1 through the buttons *video overview* and *history overview*.

Video Recording and Questionnaire: When clicking on the button "neue Aufnahme" (new recording), the user is guided through a preparation page, which can be seen in Figure 2. This includes instructions about positioning, background, and volume control and gives the option to look through all the following instructions within the video protocol or watch an example recording of such video protocol. This feature is optional since the instructions are spoken out by the app and tests on subjects have shown a good intuitive understanding. As the instructions are adapted to typical movements for assessment of the specified disease, the patient might be familiar with them. The second preparation page shows the camera view and the user sees him/herself. A human silhouette is drawn as an overlay to the camera view of the user to show the correct positioning. The user is instructed to position the camera so that the head and shoulders are clearly visible, as cervical dystonia affects the muscles in the head and neck. The user can then start the recording by clicking on a button at the bottom of the page. The recording is stopped automatically after the last instruction. Directly after the protocol finishes, the user can decide if the video should be uploaded or deleted.

Menu Button: The menu button on the main page provides access to the privacy policy, instructions for use, and information about the app in general and its goals. The privacy policy has to be accepted with the first login to the app and contains information on how the data is handled as well as contact information of the responsible data protection office of the University of Lübeck.

Tutorial Video

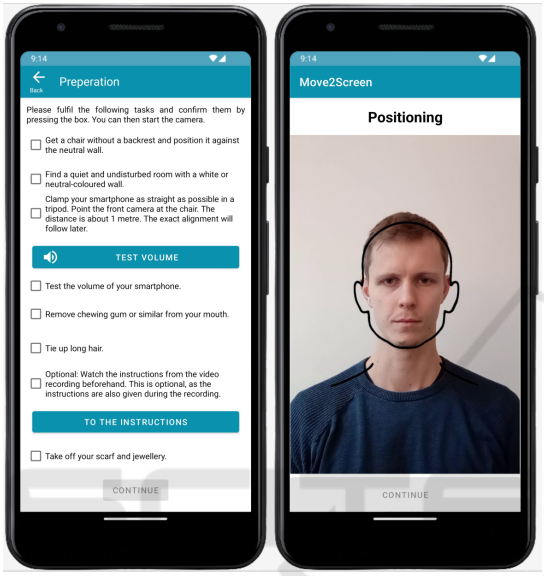

Figure 2: The two preparation pages before the guided video recording, which contain confirmation buttons for some necessary preparations a test button for the volume on the first page, and a camera view for positioning on the second page.

To help with questions about using or understanding the app, we have created a tutorial video for each aspect of the app. These points explain both the operation and the purpose/idea of the app. The following individual topics are covered by tutorial videos and can be accessed via the menu under the *Instructions for use* tab.

- Idea of the app
- Start page
- Menu
- Questionnaire
- Video recording

2.3 User Experience Study

A user experience study was conducted with a total of 10 participants, five of whom had symptoms of cervical dystonia. The remaining five participants had no symptoms. The purpose of the study was to test the acceptance and usefulness of the app. In the first part of the study, the participants were asked to navigate through the app and then,find out how to record a video. After navigating to the video recording page, the participants were asked to record a video according to the implemented protocol as second part of the study. Participants were then asked to fill out a questionnaire about the app. The questionnaire consists of an adapted version of the German mHealth App Usability Questionnaire (G-MAUQ) (Zhou et al., 2019)(Kopka et al., 2023), general questions about the age, gender, and experience with smartphones, and several free text questions aiming for the subjective impression. The questionnaire is appended. The last two question of the G-MAUQ where discarded, as 3 to 4 of the diseased subjects gave an answer at all to these questions. Each item of a total of remaining 16 items of the G-MAUQ was evaluated on a 7-point scale, ranging from 1 (strongly disagree) to 7 (strongly agree). The Q-MAUQ covers three subscales: ease of use (5 items), interface and satisfaction (7 items) and usefulness (4 items) which will be evaluated separately.

3 STUDY RESULTS

In this section, the results of the user study are presented. In Figure 3 the answers to the G-MAUQ are shown. The answers are sorted into the three groups ease of use (E), interface and satisfaction (I) and usefulness (U). The answers are given in a range between 1 and 7, where 1 means strongly disagree and 7 strongly agree. In 75% of cases, the answers given were 6 or 7 (agree or strongly agree), showing a high acceptance of the app. The average value over all participants and question groups are listed in Table 1.

Table 1: Average values of the answers to the G-MAUQ.

Group	Subjects	Avg. (Std)	Min/Max
E	Diseased	6.27 (±1.01)	4/7
	Healthy	5.64 (±0.79)	3/7
I	Diseased	6.09 (±1.16)	3/7
	Healthy	5.89 (±0.92)	3/7
U	Diseased	5.7 (±1.0)	4/7
	Healthy	5.95 (±0.59)	5/7

The answers to question 9 *(Q9: I feel comfortable using this app in social settings)* stand out here, as an average value of 4.8 (±1.6) was given. This result emphasizes that video recording of oneself, especially with the aim of recording symptoms, is an in-

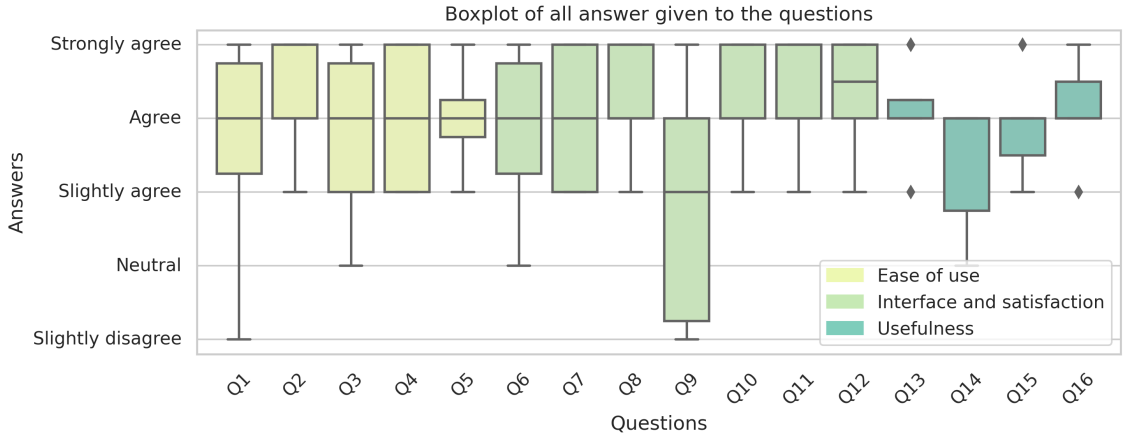

Figure 3: Boxplot of the answers to the G-MAUQ, sorted into the three groups ease of use, interface and usefulness.

timate matter. Question 14 *(Q14: The app improved my access to health care services.)* was answered with an average value of 5.4 ($\pm$0.9), and in two cases the question was left unanswered. We assume that such matter comes due to the fact, that the app was tested in the setting of the study, which was not intended to present a finished medical product, but merely to serve as a test phase, without any advantages for the diseased test subjects. For questions 11 to 16, at least two and at maximum three times, an answer was not given.

Additional to the G-MAUQ question, several text questions were asked as well (see appendix questions 22-26) and a discussion was held on the general impression of the app. Individual uncertainties regarding operation were expressed. The steps to counter these ambiguities are listed below, to name a few:

- The bottom navigation was colored to make it more visible.
- Text was added under the back-arrow, to make it more clear that it is a back button.
- One prerequisite was that the test subjects remove their glasses in order to collect the data more uniformly. This requirement was discarded due to a comment from a subject
- Within the video protocol, it was not clear in which direction the subject should rotate as part of the tasks. This was changed by adding a clearer vocal instruction.
- The silhouette that is used to show the correct positioning of the camera was not in a realistic shape of a human. This was changed to a more realistic shape (visible in Figure 2)

4 DISCUSSION

This paper presents asynchronous therapy monitoring app for cervical dystonia in order to create standardized videos that may help clinicians to derive a qualitative severity score. The app is designed for the monitor the progression of cervical dystonia, but it could be adapted to other movement disorders. First results from patients with cervical dystonia and a healthy control group indicate a high interest in the app based on the good results of the G-MAUQ. Good results in the qualitative user study groups *Ease of use* and *Interface and satisfaction* of the G-MAUQ, which both scored with a rating of over 6 (agree) of the diseased participants, underline the user-friendliness of the app. The question group *Usefulness* scored with a rating of 5.7 (agree) of the diseased participants, which is slightly below the global average of 5.94 ($\pm$0.96) and several questions in this group were not answered by each subject, so the data base on which this result is based is smaller than for the other question group. We hypothesize that this result was influenced by the context of the study. The app was evaluated during a test phase, not as a complete medical product. Consequently, this trial phase did not provide any direct benefit to the participants suffering from dystonia, which could then influence the perceived usability.

The results of the study show the interest in the app and the amount of participants (10 individuals where 5 are diseased and 5 healthy) is sufficient in our estimation, as the comments did not differ much from each other except for some minor navigation difficulties and a saturation of findings was reached¡ (Sauro and Lewis, 2012). However, not all subjects gave an answer to all questions, which shrinks the cohort on some questions. The short duration of the usability

study does not encompass the engagement and efficacy when the app is used for a long period and from home.

5 CONCLUCION

Our initial short-term usability study with a sample size of 10 participants showed promising results in terms of user acceptance and willingness to use the app. However, we acknowledge the limited duration of the individual subject tests of the app which cannot replace a study lasting several weeks. Although initial responses regarding usability are encouraging, further research is needed to investigate the clinical efficacy of the application. We aim to conduct a more comprehensive study with a larger and more diverse cohort to test the reliability and acceptance of the application for independent use over a 12-week period. This longer period will allow us to determine the level of acceptance of the app more clearly, as it requires more initiative to use independently. Subjects must invest time on a weekly basis without receiving immediate feedback. Regarding these aspects, we expect that some questions of the G-MAUQ will be more meaningful in the context of the planned study. Furthermore, the quality of the uploaded videos will also be evaluated for their medical usefulness. The app's fundamental purpose is to document the progression of symptoms over several weeks. The videos recorded in the planned study provide a data set that allows for comparison of the same time stamps between videos of the same person over a period of multiple weeks, enabling an accurate assessment of symptom progression. The implemented video protocol ensures fixed time points at which the same movement is performed. This standardized evaluation would not be possible without such a video protocol as it is implemented in the app

ACKNOWLEDGMENTS

The author thank all participants of the user study for their time and effort. We acknowledge financial support by the German Federal Ministry of Education and Research (01ZZ2007).

REFERENCES

Abdolahi, A., Bull, M. T., Darwin, K. C., Venkataraman, V., Grana, M. J., Dorsey, E. R., and Biglan, K. M. (2014). A feasibility study of conducting the montreal cognitive assessment remotely in individuals with movement disorders. *Health Informatics Journal*, 22(2):304–311.

Ben-Pazi, H., , Browne, P., Chan, P., Cubo, E., Guttman, M., Hassan, A., Hatcher-Martin, J., Mari, Z., Moukheiber, E., Okubadejo, N. U., and Shalash, A. (2018). The promise of telemedicine for movement disorders: an interdisciplinary approach. *Current Neurology and Neuroscience Reports*, 18(5).

Fraint, A., Stebbins, G. T., Pal, G., and Comella, C. L. (2020). Reliability, feasibility and satisfaction of telemedicine evaluations for cervical dystonia. *Journal of Telemedicine and Telecare*, 26(9):560–567.

Gerpen, J. A. V. (2013). Marsden's book of movement disorders. *Neurology*, 80(24):2278–2278.

Hassan, A., Dorsey, E. R., Goetz, C. G., Bloem, B. R., Guttman, M., Tanner, C. M., Mari, Z., Pantelyat, A., Galifianakis, N. B., Bajwa, J. A., Gatto, E. M., and Cubo, E. (2018). Telemedicine use for movement disorders: A global survey. *Telemedicine and e-Health*, 24(12):979–992.

Kopka, M., Slagman, A., Schorr, C., Krampe, H., Altendorf, M. B., Balzer, F., Bolanaki, M., Kuschick, D., Möckel, M., Napierala, H., Scatturin, L., Schmidt, K., Thissen, A., and Schmieding, M. (2023). German mHealth app usability questionnaire (g-MAUQ): Translation and validation study. *Center for Open Science*.

Liew, M. S., Zhang, J., See, J., and Ong, Y. L. (2019). Usability challenges for health and wellness mobile apps: Mixed-methods study among mhealth experts and consumers. *JMIR MHealth UHealth*, 7(1).

Martino, D., Berardelli, A., Abbruzzese, G., Bentivoglio, A. R., Esposito, M., Fabbrini, G., Guidubaldi, A., Girlanda, P., Liguori, R., Marinelli, L., Morgante, F., Santoro, L., and Defazio, G. (2012). Age at onset and symptom spread in primary adult-onset blepharospasm and cervical dystonia: Age and spread in primary adult-onset dystonia. *Movement Disorders*, 27(11):1447–1450.

McGraw, D. and Mandl, K. D. (2021). Privacy protections to encourage use of health-relevant digital data in a learning health system. *npj Digital Medicine*, 4(1).

Ospina Medical (2023). Conquering cervical dystonia: The power of intramuscular botox injections. [2023, April 19] https://ospinamedical.com/orthopedic-blog/conquering-cervical-dystonia-the-power-of-intramuscular-botox-injections.

Sauro, J. and Lewis, J. R. (2012). Chapter 2 - quantifying user research. In Sauro, J. and Lewis, J. R., editors, *Quantifying the User Experience*, pages 9–18. Morgan Kaufmann, Boston.

Srinivasan, R., Ben-Pazi, H., Dekker, M., Cubo, E., Bloem, B., Moukheiber, E., Gonzalez-Santos, J., and Guttman, M. (2020). Telemedicine for hyperkinetic movement disorders. *Tremor and Other Hyperkinetic Movements*, 10(0).

Zhou, L., Bao, J., Setiawan, I. M. A., Saptono, A., and Parmanto, B. (2019). The mHealth app usability questionnaire (MAUQ): Development and validation study. *JMIR mHealth and uHealth*, 7(4):e11500.

APPENDIX

Questionaire

The questionaire consists of the G-MAUQ and additional questions which are listed below. The MAUQ question which we use for our study were translated into German and validated by (Kopka et al., 2023).

Ease of Use (MAUQ)
Q1. The app was easy to use.
Q2. It was easy for me to learn to use the app.
Q3. The navigation was consistent when moving between screens.
Q4. The interface of the app allowed me to use all the functions (such as entering information, responding to reminders, viewing information) offered by the app.
Q5. Whenever I made a mistake using the app, I could recover easily and quickly.

Interface and Satisfaction (MAUQ)
Q6. I like the interface of the app.
Q7. The information in the app was well organized, so I could easily find the information I needed.
Q8. The app adequately acknowledged and provided information to let me know the progress of my action.
Q9. I feel comfortable using this app in social settings.
Q10. The amount of time involved in using this app has been fitting for me.
Q11. I would use this app again.
Q12. Overall, I am satisfied with this app.

Usefulness (MAUQ)
Q13. The app would be useful for my health and well-being.
Q14. The app improved my access to health care services.
Q15. The app helped me manage my health effectively.
Q16. This app has all the functions and capabilities I expect it to have.

General Questions
Q17. Age
Q18. Gender
Q19. Do you have any experience with smartphones? (on a scale 1-5)
Q20. How often do you use your smartphone? (less than 1x per week, multiple times per week, daily)
Q21. What do you use your smartphone for? (phone calls, chat/social media, gaming, streaming, internet research, organization)

Free Text Questions
Q22. For which functions unexpected errors have occurred?
Q23. What about the app did you not understand or find it too complicated?
Q24. Which functions did you miss?
Q25. Which functions do you find superfluous?
Q26. Do you have any further comments or suggestions for improving the app?