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Research Article

Enhancing migraine care and research through Telemedicine and telemonitoring: E-diary tracking and home EEG.

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ABSTRACT

Background: New acute and preventive treatments have expanded migraine care options, highlighting the need for integrated, personalized management strategies. Telemedicine and telemonitoring support multidisciplinary approaches and are essential tools in optimizing patient outcomes.**Objectives:** This study aims to demonstrate the usability and user-friendliness of a validated E-diary and a self-administered electroencephalogram (EEG) telemonitoring setup for migraine care and research.**Methods:** E-diary data were collected from adult migraine patients at the Leiden Headache Center to assess compliance, with patient satisfaction evaluated through questionnaires. In a separate component of the study, the user-friendliness of a home-based EEG setup for migraine research was examined. Participants completed two measurement sessions on different days, with varying intervals between sessions. Evaluation measures included the System Usability Scale (SUS), task completion time, electrode connection success, and overall user experience.**Results:** Migraine patients (n = 753) were followed for a median of 353 [IQR 128–697] days. Compliance was 96.7 % [IQR 88.1–99.6]. The E-diary received a median score of 7/10, 66.0 % of patients reported being (very) satisfied with the E-diary app. The EEG setup was tested by 20 participants and awarded a high SUS-score of 91.2 [IQR 86.2, 95.0].**Conclusion:** Telemedicine and telemonitoring offer scalable, effective solutions for advancing both migraine care and research. Telemedicine with the E-diary may enhance personalized, integrated migraine care. Compliance and satisfaction with the E-diary are high. Self-administered telemonitoring using remote EEG setups demonstrates the feasibility of conducting complex studies in home-based settings.

Plain language summary

With more treatment options now available, migraine care needs to incorporate more personalized monitoring. Telemedicine and telemonitoring tools can help make this possible. This study explored how well two digital tools could support people with migraine in both care and research: an electronic headache diary (E-diary) and a home-based brain monitoring system using an electroencephalogram (EEG). We wanted to find out if patients could easily use these tools at home and if they found them helpful.

We collected E-diary data from 753 adult migraine patients at the

Leiden Headache Center to measure compliance and how satisfied they were with the app. In a separate part of the study, 20 participants tested a home EEG device during two sessions on different days. We looked at how easy it was to set up, whether the electrodes were connected properly, and how user-friendly the process was.

Patients showed high compliance with and satisfaction toward the E-diary. The app was positively rated for helping users follow physician instructions, its user-friendliness, and the clarity of information and notifications. Participants also evaluated the self-administered EEG setup favorably. They found it easy to use, noted improvements with

Abbreviations: CGRP, Calcitonin gene-related peptide; E-, Electronic; E-diary, Electronic diary; EEG, Electro-encephalogram; E-tools, Electronic tools; ICHD, International Classification of Headache Disorders; IQR, Interquartile range; LUMC, Leiden University Medical Centre; PROMS, Patient Reported Outcomes; SD, Standard deviation; SUS, System usability scale; VEP, Visual evoked potential.

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repeated use, and rated the overall experience positively.

This study shows that telemedicine and home-based monitoring are practical, user-friendly options for migraine care and research. The E-diary can support more personalized treatment, while the EEG system shows that even complex studies can be done at home with proper guidance.

1. Introduction

The emergence of new acute and preventive treatments has expanded migraine care options, emphasizing the need for integrated, personalized management strategies. Telemedicine and telemonitoring support this approach by enabling (multidisciplinary) care and offering new perspectives on treatment. Telemedicine refers to the remote delivery of clinical services using telecommunications technology, such as virtual consultations, diagnosis, treatment planning, and follow-up and may incorporate tools like electronic diaries to track symptoms, enhance communication, and tailor care. It serves as an effective alternative to traditional in-person visits, maintaining comparable quality of care. Telemonitoring involves the remote collection and transmission of health data, including physiological metrics such as electroencephalogram (EEG) or blood pressure, making it particularly suitable for migraine research and management. With validated tools, telemonitoring allows for efficient, home-based tracking for care and research with Patient-Reported Outcome Measures (PROMs), and EEG recordings.

In migraine care, it is often needed to quantify the frequency of migraine by determining the number of monthly migraine days, monthly headache days, and monthly acute medication days to assess treatment response. In an earlier study by our group, recall bias between self-reported and actual recorded monthly migraine days was demonstrated [1,2]. This emphasizes the necessity for a daily headache-diary. The Leiden E-headache diary is time-locked and based on validated algorithms to determine when a day is a migraine day, headache day, and an acute medication day [1,3]. The Leiden E-tools include screening, extensive headache, comorbidity and (prophylactic) medication history questionnaires, in addition to the daily E-diary [1,4,5], [6]. Typical other PROMs can be assessed as well and easily implemented, although they are still less commonly used as clinical trial outcomes compared to monthly migraine days [7]. Most importantly, our E-diary is unique in that it uses a validated AI-algorithm to determine whether a headache day qualifies as a migraine day. In contrast, most other E-diaries rely solely on patients' self-reports that they had a migraine day, often without sufficient detail or validation. In addition, based on feedback we have received from our patients and from the European Headache and Migraine Alliance (EHMA), we consider it important to evaluate the user-friendliness of our E-diary as well.

In migraine research, new telemonitoring tools, alongside E-diaries, are increasingly emerging. This is particularly relevant in the field of attack prediction, where situational prevention using novel drugs such as gepants (CGRP-antagonists), that can be used both acutely and preventively, may be especially effective [8–10]. Previous research by our group suggested that EEG responses to visual chirp stimulation, or visual evoked potentials (VEP-EEG), might help detect early changes in cortical responsivity before an attack [11]. To replicate these findings on a larger scale, home-based EEG measurements are urgently needed, in combination with the E-diary to define interictal, preictal and ictal phases of migraine attacks. Therefore, the E-diary and EEG setup are inextricably linked. A setup was developed for migraine patients to perform their own EEG measurements at home with E-tools and a cap with water-based electrodes. The signal quality of water-based electrodes is comparable to that of traditional gel-based systems, and water-based electrodes are easier to use than gel-based electrodes [12,13].

This study explored the practical utility and user-friendliness of two complementary tools in migraine care and research: the E-diary and the EEG telehealth setup. Patient satisfaction with the E-diary, as well as

System Usability Scale (SUS) scores, setup completion times, successful electrode connection rates, and overall user experience for the EEG setup, were assessed to evaluate their integration into clinical and research settings.

2. Methods

2.1. E-diary study design

Patients were enrolled between February 2022 and May 2025. They used the E-diary within the Patient Journey App (PJA) for at least one month and completed a standardized PJA questionnaire assessing their satisfaction [1,5]. Additionally, E-diary compliance was evaluated.

The Medical Ethics Committee of the Leiden University Medical Center (LUMC) judged that this study as not being associated with ethical concerns. Therefore, participants were not required to provide additional informed consent. All data were analyzed in a fully anonymized setting.

2.2. E-diary participants

Inclusion criteria were ≥ 18 years, an active migraine diagnosis, proficiency in Dutch. Upon enrolment, participants completed a validated electronic headache questionnaire and recorded daily entries in the E-diary for at least one month [1,4]. The diary captured headache activity, symptoms, aura presence, acute medication use, and changes prophylactic treatment. A validated algorithm classified days as migraine, headache, non-headache [3,14]. Diagnoses were confirmed by a physician in consultation with a headache-specialized neurologist (GT), based on ICHD-3 criteria [14].

2.3. E-diary app

The E-diary, embedded in the Patient Journey App, sends daily notifications at 8 a.m. to 6 p.m. to encourage entries. It is time-locked after 48 h to reduce recall bias. The app developer holds ISO27001, ISO9001, and NEN7510 certifications and undergoes privacy audits quarterly to ensure GDPR compliance. Data access is role-based for healthcare professionals only, with researchers accessing anonymized data. Patients log in via a unique code and can enable additional security such as biometric access.

2.4. E-diary outcomes

E-diary compliance was measured as the percentage of completed entries during each participant's follow-up, which varied individually. Participants' satisfaction with the E-diary in the Patient Journey App was assessed via the PJA questionnaire, including an overall experience score (0–10), ratings of information and push-notification amounts, and sliding-scale evaluations (0–100) of usability, support in following physician instructions, and likelihood to recommend the app.

2.5. EEG study design

Participants received an instruction guide and a demonstration before performing two EEG measurements independently, on two separate days. Afterwards, they completed questionnaires assessing usability, SUS-score, completion time, and number of electrodes connected. The completion time measurement began when participants started reading the instruction guide. The number of electrodes connected was chosen as a task metric because of its simple user application. It is currently still being researched if this leads to adequate impedance values. The study was approved by the LUMC Ethics Committee (P24.025), and all participants gave written informed consent. Data were collected between November 2024 and January 2025.

2.6. EEG participants

Participants were ≥18 years old, Dutch-speaking, and did not need a migraine diagnosis, as only setup usability was assessed. Exclusion criteria included (photosensitive) epilepsy, sensory impairments, and prior EEG experience.

2.7. EEG outcomes

The primary endpoint was the SUS-score, with a score ≥68 indicating above-average usability [15]. Possible predictors of higher SUS-scores were also explored. Secondary outcomes included completion time, successful electrode connection, and participants’ overall experience across both measurement days.

2.8. EEG equipment

An overview of the complete setup is shown in Fig. 1. The setup included a wearable EEG-measuring device (APEX)with a water-based Infinity head cap (TMSi – an Artinis Company, the Netherlands). The headcap featured seven electrodes: one frontal electrode (Fz), three central electrodes (C3, Cz and C4) and three occipital electrodes (O1, Oz and O2). The ground electrode was placed on the wrist by a wristband. A study phone was added to the setup to allow participants to see if they placed the cap correctly on their head. To be able to capture the responses to VEP-stimulation, a trigger box and LED-goggles were used. The trigger box controlled the LED-goggles to provide light flashes intermittently when required, and played auditory cues to indicate different phases of the measurement protocol.

Per measurement day, two types of measurements were conducted. The VEP-EEG protocol and the Resting State protocol. For the Resting State protocol, participants alternated between opening and closing their eyes every minute for a total of 5–6 min (cued by the tones played through the trigger box). For the VEP-EEG protocol, participants put on the LED-goggles, through which light flashes consisting of a brief sequence (~6 s) with a rapidly increasing stimulation frequency from 10 to 40 Hz were emitted (three pulses at each frequency). This stimulation protocol was repeated 12 Times with a 10–15 s break while participants had their eyes closed.

2.9. Statistical analysis

Data cleaning and analysis were conducted using R statistical software (R version 4.2.1; R Foundation for Statistical Computing, Vienna Austria, 2016; URL: <https://www.R-project.org/>). For baseline characteristics, descriptive statistics were used and summarized as medians with IQRs or frequencies with proportions. E-diary satisfaction data gathered by the sliding scale (0-100) was transformed to a 5-point categorical scale. The sample size for the EEG setup evaluation part of the study was determined based on the original validation study of the System Usability Scale, which demonstrated that 20 participants are sufficient for valid usability assessments [15]. A Wilcoxon signed-rank test was performed to compare the SUS-score of the EEG setup to the benchmark SUS-score of 68. Linear regression was used to identify possible predictors of a higher SUS-score. Averages were used to describe the secondary outcomes: completion time, number of electrodes successfully connected out of 7, and overall experience. Additionally, to identify a possible learning curve per participant, the difference between the first and second session for completion time was evaluated with a linear mixed-effects model, with time in-between sessions as a covariate.

3. Results

3.1. E-diary study population

Between February 2022 and May 2025, 811 migraine patients used the E-diary and completed the satisfaction questionnaire. After excluding 46 with <1 month of follow-up and 12 incomplete questionnaires, 753 participants remained. Baseline characteristics are shown in

Table 1A
Baseline characteristics of E-diary participants.

	E-diary questionnaire participants
Number of participants, n	753
Years of age, median [IQR]	48 [39,56]
Female sex, n (%)	630 (83.8)
Migraine with aura diagnosis, n (%)	218 (29.0)
E-diary compliance (%), median [IQR]	93 [73–99]



Fig. 1. Overview of EEG setup.

Table 1A.

3.2. E-diary compliance

Median follow-up was 353 days [IQR 128–697], with 6.8 % of 433,889 total days missing. Median compliance was 96.7 % [IQR 88.1–99.6], and 86.1 % (648/753) of participants achieved ≥ 80 % compliance (Fig. 2A).

3.3. E-diary patient satisfaction

The 753 participants gave the E-diary a median satisfaction score of 7 [IQR 7–8] (Fig. 2B), with 66.0 % reporting being (very) satisfied (Fig. 2C). The diary was considered neutral to (very) useful for following physician instructions by 66.7 % (Figs. 2D), and 85.3 % rated its user-friendliness as (very) high (Fig. 2E). Most participants found the amount of information (72.5 %) and push notifications (82.7 %) adequate (Fig. 2F–G). Finally, 62.9 % would probably or definitely recommend the app (Fig. 2H).

[Insert Fig. 2A–H]

3.4. EEG study population

Twenty participants completed two self-administered EEG measurements on separate days (mean interval: 6.7 ± 8.4 days). All completed the questionnaires, with no dropouts. Baseline characteristics are shown in Table 1B.

3.5. EEG SUS-score

Median SUS-score of the participants that evaluated the setup was 91.2 [86.2, 95.0], as shown in Fig. 3A. This exceeded the SUS-score benchmark of 68.0 ($p < 0.001$), which deems a setup sufficiently user-

Table 1B

Baseline characteristics of EEG setup participants.

	EEG setup participants
Number of participants, n	20
Years of age, median [IQR]	26 [16]
Female sex, n (%)	13 (65)
Migraine diagnosis, n (%)	4 (20)
Highest educational level, n (%)	
Primary education	1 (5)
VMBO ¹	0 (0)
MBO ²	0 (0)
HAVO/VWO ³	9 (45)
HBO ⁴	5 (25)
WO ⁵	5 (25)
Confidence in technical capabilities, n (%)	
None	1 (5)
Somewhat	19 (95)
High	0 (0)

¹ Pre-vocational secondary education

² Secondary vocational education

³ Senior general secondary education/pre-university education,

⁴ Higher vocational education

⁵ Scientific/academic education

friendly. Linear regression analyses showed that age ($p = 0.24$), sex ($p = 0.08$), educational level ($p = 0.12$) and confidence in technical capabilities ($p = 0.49$) were not correlated with a higher SUS-score.

3.6. EEG completion time

Mean completion time was 25.1 min (CI: 23.7 – 26.5) for measurement day 1, and 21.8 min (CI: 20.4 – 23.2) for measurement day 2. The reduction in completion time from the first measurement to the second measurement was significant; -3.3 min, $p < 0.001$. Completion time



Fig. 2. A-H. E-diary compliance and satisfaction. E-diary compliance. Satisfaction Grading on 10 points scale (0–10, 0 = extremely dissatisfied, 10 = extremely satisfied). Level of satisfaction on 5 point scale (very unsatisfied–very satisfied). Usefulness of E-diary in following physician’s instructions (no–high). User-friendliness of E-diary (no useful–very high useful). Amount of information in E-diary (not enough–adequate–too much). Amount of push notifications in E-diary (not enough – too much). Probability of recommending E-diary to others (definitely no–definitely yes).

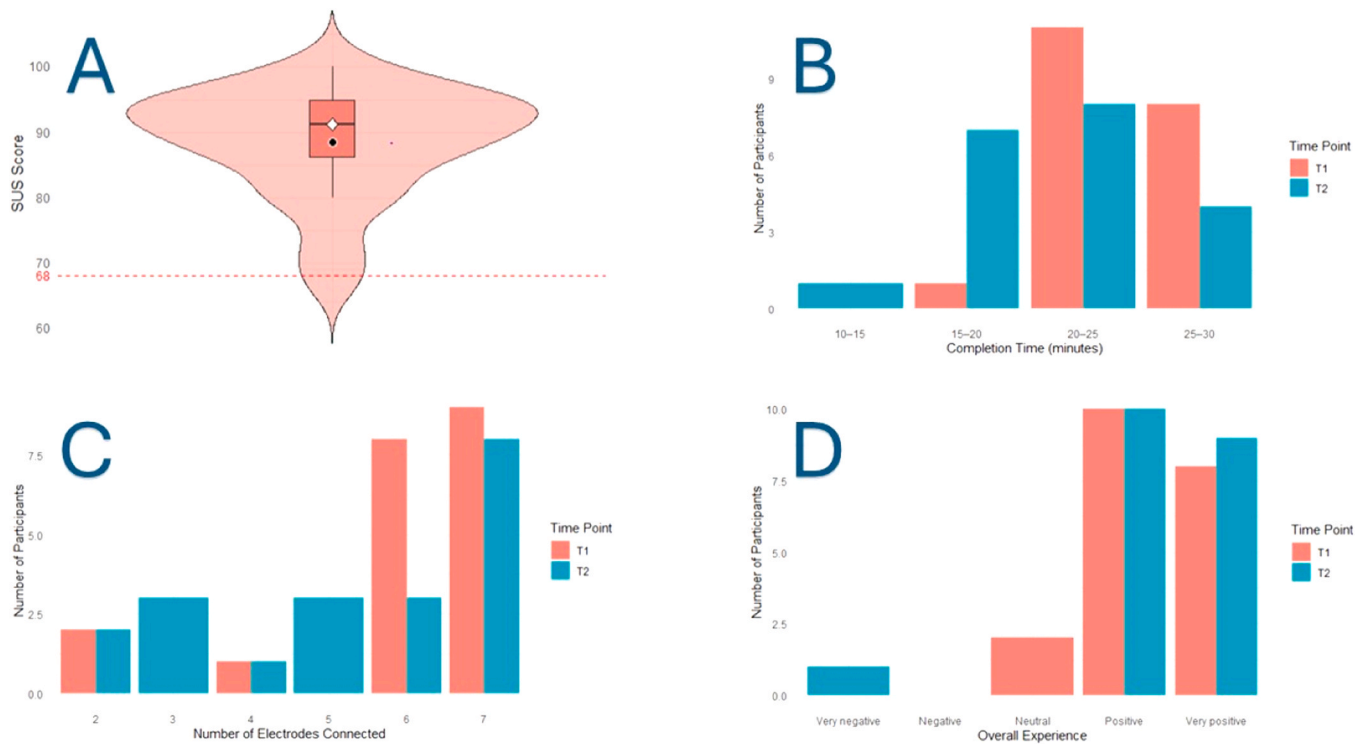


Fig. 3. A-D. EEG setup satisfaction. SUS-score rating of EEG setup. Completion time distribution of EEG setup. Number of electrodes successfully connected out of 7 for EEG setup. Overall experience ratings of EEG setup.

distribution per 5 min intervals is shown in Fig. 3B; most participants completed the measurements between 20 and 25 min (11/20 for time point 1, and 8/20 for time point 2).

3.7. EEG electrode connection

The median number of electrodes that were successfully connected was 6/7 [4,7] across all measurements (Fig. 3C). At time point 1 an average of 85 % of electrodes were successfully connected versus 76 % at time point 2, with an odds ratio of 2.1 (CI: 1.1 – 4.0, $p = 0.03$.)

3.8. EEG overall experience

Participants rated their overall experience with the setup with a median grade of 4/5 [4,5], which corresponds to an overall positive experience (Fig. 3D).

3.9. EEG feedback

The most frequently commented positive feedback included the photographs in the instruction guide, and the explanation beforehand by the researcher. The main difficulty for participants was determining when a sufficient connection between their scalp and the water-based electrodes had been established, a visual feedback system on the correct placement of the electrodes was recommended. Other challenges were the fragility of some cables, reading the instruction guide without reading glasses, and confusion with device names. Suggestions for improvement included shortening the procedure, including more photographs, and implementing different cap sizes.

4. Discussion

Patients showed high compliance with and satisfaction toward the E-diary, indicating strong usability and acceptance. The app was positively rated for helping users follow physician instructions, its user-

friendliness, and the clarity of information and notifications. Participants also evaluated the self-administered EEG setup favorably. They found it easy to use, noted improvements with repeated use, and rated the overall experience positively. These results show that telemonitoring can reliably be implemented in more and more aspects of migraine care and research while being highly user-friendly. Further research to interpret the EEG results, will need the E-diary to determine during which phase an EEG recording took place (interictal-preictal-ictal-postictal). By doing so, preictal cortical excitability changes might be used to predict attacks.

The E-diary has several practical applications. Since patients with migraine often cannot reliably recall their migraine days, tending to overestimate when experiencing more than eight MMD and underestimate when having fewer than eight, an e-diary is frequently necessary [1]. Paper diaries lack time-stamped entries, which can lead to patients retrospectively filling in data, introducing recall bias. Additionally, another study demonstrated that when investigating trigger factors, even the most obvious trigger, such as menstrual bleeding, cannot be reliably recalled without the use of an e-diary [17]. In one study, its use revealed that perimenstrual migraine attacks in women with menstrually-related migraine last longer, increasing the risk of recurrence and triptan overuse, underscoring the need for female-specific treatment [18]. In another study, the E-diary enabled accurate tracking of monthly migraine days, showing that switching between different classes of CGRP monoclonal antibodies led to improved outcomes in patients with inadequate initial response [19]. Additionally, the E-diary proved valuable for evaluating preventive treatments and was used for reimbursement guidelines in the Netherlands. In ongoing research, it supports real-world comparisons of preventive treatments for tolerability and effectiveness. For the EEG setup, usability was assessed using the System Usability Scale (SUS). While prior studies focused on simpler tasks like vital sign monitoring [20], this study required participants to independently perform EEG recordings. Results demonstrate that complex telemonitoring is feasible when supported by a well-designed system.

This study has several strengths. It used a large, well-defined migraine group of participants to assess user-friendliness of the E-diary. E-diaries support shared decision-making, improve treatment evaluation, and help reduce costs by identifying ineffective therapies [21]. For the EEG setup, usability was assessed with the validated SUS-score, along with task metrics like completion time and successfully connected electrodes. Both qualitative and quantitative methods were used, including repeated measurements to assess learning effects and participant feedback to inform future improvements. This study also has some limitations. For the E-diary, selection bias may exist, as academic hospital patients might be more compliant. However, similar results from non-academic hospitals in the Netherlands suggest generalizability, and the Leiden Headache Center also treats patients referred directly by general practitioners. The EEG setup evaluation was limited by a small, relatively homogeneous sample. Although the sample size was justified by SUS-score validation studies, future testing should involve a more diverse group. Electrode connection issues occurred due to a lack of visual feedback. This has been improved in a subsequent version of the setup. While impedance values are commonly referenced to assess electrode connection in EEG setups [22,23], this study did not evaluate impedance, as its focus was solely on usability and user-friendliness. Ongoing research is evaluating the importance of impedance values, as compared to just the number of electrodes that were successfully connected.

With improved EEG instructions, combining the E-diary with an updated EEG setup could enable reliable, user-friendly home-based recordings. These could help monitor cortical excitability in the preictal migraine phase, supporting attack prediction and the development of situational prevention strategies, which is now feasible with new treatments such as gepants. Further research will implement an optimized EEG setup in a large migraine cohort that is also using the E-diary. This will allow us to combine both tools effectively towards predicting upcoming migraine attacks.

CRediT authorship contribution statement

M. van de Ruit: Writing – review & editing, Conceptualization. **G.M. Terwindt:** Writing – review & editing, Methodology, Conceptualization. **J.L. Duijvelshoff:** Writing – review & editing, Conceptualization. **Oosterlee Annemijn:** Writing – original draft, Methodology, Formal analysis, Conceptualization. **B.W.H. van der Arend:** Writing – review & editing, Conceptualization.

Ethics approval and consent to participate

The study is performed in accordance with the declaration of Helsinki Ethical Principles and Good Clinical Practices and was approved by the local ethics committee.

Consent for publication

Not applicable.

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Declaration of Competing Interest

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Not applicable.

Data availability

The data that support the findings of this study are available from the corresponding author, G.M. Terwindt, upon reasonable request.

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