

# Improving Self-Report Diaries: A Respondent-Centric Design Approach

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**Abstract:** Medical self-report plays an indispensable role in healthcare, capturing vital subjective data from health and everyday life contexts. While considerable research has been dedicated to trialling self-report to ensure their clinical validity, there has been less focus on understanding user behaviour in self-reporting and on devising strategies to optimise the use of these self-report tools. The traditional approach to self-report design has been largely information-centric, relegating patients to the role of passive information providers. This can lead to a significant respondent burden due to the retrospective nature of the questions and the inherent challenges in data provision. Recently, the Respondent-centric Design (RxD) Framework has been suggested as an approach to bridge clinical needs and patient's needs within the self-report design process. In this paper we report on the use of the RxD framework for redesigning a headache diary. Our experience on using RxD provides insight into its potential to reshape self-report design, RxD steered our focus during the redesign to consider respondent perspectives more thoroughly. The redesigned headache diary received positive feedback, both from users and experts, and the evaluation suggests improved adherence and higher respondent acceptance.

## 1 INTRODUCTION


Recent advancements in patient-centric healthcare emphasise patient involvement in treatment, making self-reporting an indispensable tool. The Respondent-centric Design framework (RxD), grounded in Interaction Design (IXD) principles, has been introduced (Barendregt and Wasson, *subm*) to elevate the quality of self-reported data by alleviating respondent burden. RxD, specifically tailored specifically for patient-centric healthcare self-reporting, emphasises incorporating patients' perspectives throughout the design process. Situated at the intersection of self-reporting, interaction design, and patient-centric care, RxD places emphasis on the respondent. It focuses on facilitating the creation of interfaces that resonate with patients, aiming to transform self-reporting from a tedious task to a meaningful, engaging activity. This approach is designed to minimise response errors and biases, which directly results in more reliable data for healthcare decisions. By enhancing the usability and sustainability of the designs, RxD facilitates greater patient engagement and empowers them to be active,


informed decision-makers in their healthcare journey. As a result, these intuitive and sustainable designs enhance the patients' autonomy and empowering them to be active, informed decision-makers.


This paper primarily aims to illustrate the benefits of RxD as a user-centred design approach on data quality and respondent burden in self-report diaries. It describes the methods and evaluation techniques adopted during the redesign and evaluation of a self-report headache diary, integrating respondent perspectives. The redesigned diary serves as a practical example, illustrating the effectiveness and application of a respondent-oriented process in the development of self-report tools.

Headache diaries are important tools for tracking headaches and diagnosing related conditions, typically used by patients between general practitioner referral and neurologist consultation to record pain timing, intensity, and medication use. In designing mobile headache diaries, a key challenge is balancing usability with clinical requirements (Hundert et al., 2014). Usability facilitates accurate data entry by patients, while clinical relevance ensures the data's medical utility. Yet, usability often remains under-addressed in many existing applications (Hundert et al., 2014).

The Norwegian Directorate of Health recom-

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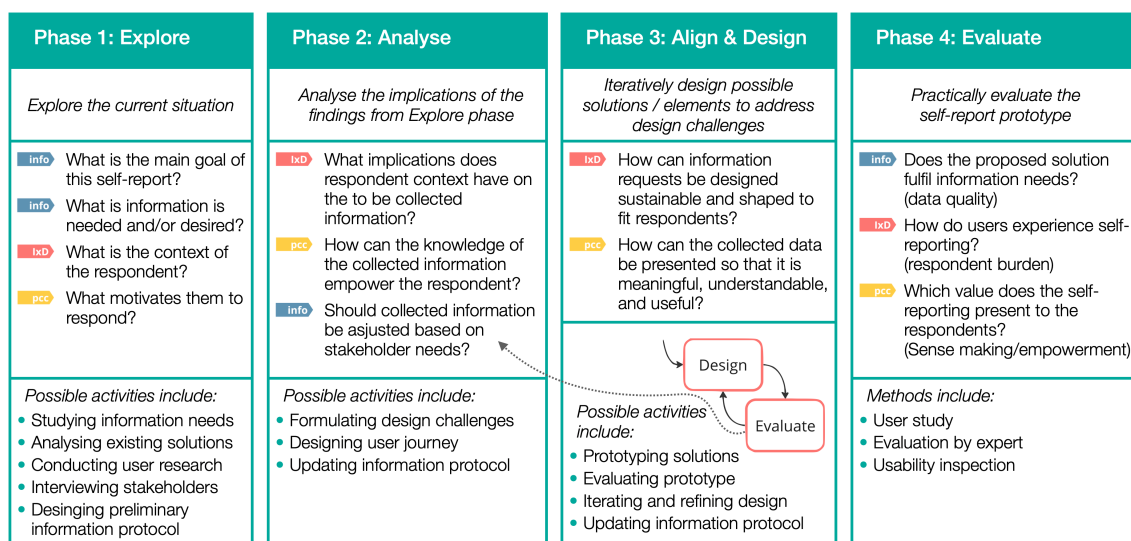


Figure 1: The four phases of the RxD framework, from (Barendregt and Wasson, subm).

mends the use of the Brain Twin app<sup>1</sup>, developed by the Norwegian University of Science and Technology and St Olav University Hospital. Such a recommendation emphasises the app’s clinical relevance and positions it as a foundational tool to collect headache data for clinical assessment and research. However, despite its prominence, as of 20th of December 2023, the app’s moderate user satisfaction score (2.9 in Google Play, based on 52 reviews) indicates a need for improvements in patient-oriented features. This gap between clinical relevance and user satisfaction highlights the necessity of aligning clinical needs with user experience in headache diary design.

In response to this need, our study adopts the RxD framework to balance these aspects in the redesign of the headache diary. Our goal is to improve user interaction elements, thereby reducing respondent burden and enhancing the quality of information gathered.

The redesign of the headache diary was guided by the RxD frameworks iterative four-phased process: Explore, Analyse, Align & Design, and Evaluate, see Figure 1. In each phase, we employed specific methods, including desk research to review existing literature and analyse other tools, conducting interviews, and identifying design challenges. Key to this process was the development and evaluation of iterative prototypes, complemented by usability testing and inspection. Throughout the redesign process we prioritised the respondent perspective, identifying and addressing weaknesses in the original diary design. This approach ensured that the redesign focused on enhancements that directly benefited the respondents. By ap-

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plying the RxD framework, we placed the patient at the core of the design process, aiming for a balance between the clinical needs of healthcare providers and what patients find meaningful to share.

In our redesign, we integrated ‘NOW Interactions’, a mobile communication technique (Barendregt and Wasson, 2022). This approach was specifically chosen to simplify and optimise user interactions. The primary goals were to enhance information collection and address critical issues such as minimising respondent burden, boosting data accuracy, and overall enhancing the user experience in the self-report headache diary.

Integral to user-centred processes and the RxD is the early testing of interfaces and interaction mechanisms, even before trials with end-users, to identify and rectify issues with interactions. Importantly, in this early stage testing beneficial insights can also be derived from non-end users with similar traits or through simulated environments. In the context of self-reporting in digital health, this allows for effective evaluation without jeopardising patient care (Cassano-Piché et al., 2015).

By preemptively detecting and addressing user interface and interaction issues, it is more likely that when actual patients test the system they can concentrate on assessing if the solution truly fits their needs, purpose, and situation, without being sidetracked by primary usability concerns. This makes their feedback more valuable and streamlines the testing process as it allows for more rapid and efficient evaluation of issues related to respondent burden (self-reporting as difficult, time consuming, and stressful), rather than on interface and interaction issues.

The remainder of this paper is structured as follows: First, we present the process and key activities within RxD. Then, we present the results of the re-design process, including the main outcomes with regard to respondent burden and data quality. Lastly, we discuss the implications of our findings related to the use of RxD in medical self-reporting and highlight areas for future research in the conclusion.

## 2 METHODOLOGY

This section identifies the participants, and outlines how the distinct phases of RxD were applied in the context of redesigning a headache diary.

### 2.1 Participants

In the redesign's exploration and evaluation phases, we involved a neurology professor and an experienced headache diary user, providing both clinical and user-based insights. The primary participants for evaluating the prototype were teachers from various primary and secondary schools. Here are details of the participants and their participation:

*Profile and Inclusion:* 13 teachers were introduced to the NOW Interactions Headache Diary during a workshop on interaction design. Out of the group, six teachers met the inclusion criteria, which involved having an Android device, installing the prototype, and providing informed written consent for their data to be used to refine the prototype, excluding any medical analysis or implications.

*Rationale for Participant Selection:* We selected teachers for initial testing to assess the diary in a controlled, risk-free environment, to refine the interaction before involving patients in future clinical assessments, thereby minimising patient burden at this stage. Notably, the five teachers who completed the testing reported experiencing headaches, emphasising the relevance of their feedback for the diary's design.

*Duration:* The study spanned 2 weeks, during which participants were sent three daily inquiries, plus additional ones if headaches were indicated. In total, 41 to 82 inquiries were sent to each teacher during the study period.

*Incentives:* No incentives were offered, as the aim was to measure genuine adherence without external motivation. The inquiry content was designed to be engaging enough to naturally motivate participation.

*Ethical Considerations:* Ethical approval was obtained through the university's system for risk and compliance for processing of personal data in research, as the study did not involve patients and data

was only used to assess the prototype. Using patients would have required a longer process to obtain approval from the regional committee for medical and health research ethics. Though the study did not involve patients, the selected participants provided valuable feedback on user interactions, guiding future design and preparation for patient testing in later stages. Refining and optimising interactions first with non-patients strategically postpones patient involvement. This approach aims to minimise imposed burden and increase the significance of their feedback during the clinical viability assessment of the headache diary in subsequent stages.

### 2.2 Phase 1: Explore

This phase aimed to explore headache reporting, identifying key stakeholders (patients and clinicians) and their perspective. It focused on understanding the required information, the context in which patients provide it, and evaluating existing headache reporting solutions. Key activities included:

*Studying research literature.* To understand the known challenges relating to headache self-reporting. Criteria: Relevant, peer-reviewed articles or encyclopedia entries, written in English, focusing on self-report (design) or challenges related to headaches.

*Analysis of recommended app (Brain Twin).* To identify potential opportunities for improvement based on existing features, user interactions and interfaces, user reviews.

*Headache diary app comparison.* To identify design features linked to user satisfaction and uncover opportunities for new designs. Criteria: Android apps available on google play with a user rating above 3.0, and allow for headache registration; Search terms used: 'headache diary', 'headache tracking', and 'hodepinedagbok' (Norwegian for headache diary) This resulted in the inclusion of 5 apps.

*Interview with domain expert.* To gain a clinical perspective on headache reporting and identify information needs. Criteria: neurologist with experience with headache diaries.

*User interview.* To gather patient perspectives and experiences with diary app use. Criteria: used a mobile headache diary for over two months.

### 2.3 Phase 2: Analyse

This phase focused on analysing the headache reporting domain, synthesising insights from the data from Phase 1, and understanding the impact of stakeholder needs on the problem. It involved formulating design challenges and exploring possibilities that ad-

dress these challenges. Key activities included:

*Designing a user journey.* To map key contact moments where users interact with the app.

*Formulating design challenges.* To pinpoint specific issues that need to be addressed in the redesign.

## 2.4 Phase 3: Align & Design

This phase involved iteratively creating potential design solutions that align patient needs and preferences with information requirements, addressing earlier identified challenges. A variety of design and evaluation methods were used to refine these solutions. Key activities included:

*Prototype solutions.* To explore design elements that could improve user experience.

*Evaluate prototype by self-testing, user feedback, and usability tests.* To assess if user needs are met.

*Iterate and refine design.* To continually improve the prototype based on feedback and test results.

## 2.5 Phase 4: Evaluate

In this phase, the focus was on evaluating the design's effectiveness with respect to information quality, timeliness, respondent burden, and user experience. Key activities included:

*Quantitative usability test.* To measure user acceptance and adherence. Details: two weeks, 6 teacher participants, 3 daily initial inquiries. Criteria: Android phone users, successful app installation

*Engagement evaluation.* To measure user engagement in eHealth technologies. It was translated to Norwegian and adapted to assess the solution's potential for future use.

*Domain expert interview.* To gather clinical feedback on the proposed solution. Criteria: a neurologist experienced in headache diaries.

*User interview.* To collect feedback on proposed solution. Criteria: experienced headache diary user.

*Usability inspection.* To assess system efficacy and potential reduction in respondent burden by estimating the number of interactions + time spent.

# 3 RESULTS

This section presents key results from the redesign process using the RxD framework, highlighting how user interaction and interface design impact quality, timeliness, and respondent burden in a medical self-report headache diary. Rather than reconstructing the entire application, we focused on identifying specific areas with potential for significant improvement.

The findings provide practical insights into how each phase's outcomes informed the following ones.

## 3.1 Explore Phase

The *literature study* revealed that self-reporting by patients with headaches, especially in retrospective formats, poses challenges due to pain related cognitive impacts, such as memory and attention issues (Araújo et al., 2012; Barsky, 2002). These impacts make answers to retrospective inquiries, such as the severity of their headache unreliable (McKenzie and Cutrer, 2009). Memory errors can compromise data reliability, affecting overall data quality (Barsky, 2002).

Yet, headache diaries typically rely on retrospective data collection methods. Mobile apps, like Brain Twin, use push notifications to prompt logging, with reminders like "Have you remembered to register a headache today?" (translated from Norwegian), which inherently promote retrospective recall.

Further *analysis of the Brain Twin app* showed that among various elements it most prominently displays headache intensity, medication intake, and menstruation for logging. The app offers a wide range of options for presenting headache data, and notably marks dates without data as headache-free. We conducted a *comparative analysis* of Brain Twin against higher-rated Google Play apps and later included our prototype, NOW, in the comparison. The findings are summarised in Table 1.

Our comparison showed that all apps allowed for the *information* registration of headache intensity and medication use or notes. Some offer additional details like headache duration or location (e.g., left temple).

Regarding *interactions*, most apps supported a retrospective approach, either requiring users to remember to log data or providing a daily reminder. One app allowed the setting of multiple reminders, and another allowed ongoing headache registration. The simplest in-app registration process required a minimum of five interactions to log headache intensity.

As for *feedback visualisation*, there was a variety of approaches across the apps. However, a common issue was the inaccurate display of data for days without headaches, a significant oversight.

A semi-structured *interview with an experienced headache diary user* revealed challenges like forgetting to log headaches and difficulties in retrospective recall, with instances of neglect due to forgetfulness or feeling 'lazy'. Additionally, an *interview with a neurology professor* specialising in headache monitoring validated the self-report challenges identified in our study, confirming their clinical significance.



Table 1: Summary of comparative analysis of Brain Twin, NOW, and other highly ranked headache diary apps.

app + downloads <small>data as of 20th Dec 2023</small>	rating + reviews	information	interactions: type + min amount to log intensity (incl open /exit app)
<i>Brain Twin</i> 10K+ d/l	2.9 (52 reviews)	- 10 intensities + no headache - medication intake / note - menstruation / length / location	- reminder 1x a day - adjustable time - in-app registration
<i>Hodepinedagboken</i> 10K+ d/l	4.2 (118 reviews)	- 3 intensities + no headache - medication intake / note - length / menstruation	- reminder 1x a day - adjustable time - in-app registration
<i>Migraine Log</i> 10K+ d/l	4.3 (511 reviews)	- 3 intensities + aura only - medication intake / note	- no reminder - in-app registration
<i>Migraine Buddy</i> 1M+ d/l	4.6 (55.6K reviews)	- 10 intensities + no pain - medication intake - still occurring + very many var	- reminder 1x a day - adjustable time - in-app registration
<i>Headache Log*</i> 100K+ d/l	4.4 (1040 reviews)	- 10 intensities - medication intake / note - duration / location + many var	- in-app registration * we could not download app
<i>Manage my Pain</i> 100K+ d/l	4.4 (3.73K reviews)	- 10 intensities + no pain - note + many var	- as many as desired - adjustable time - in-app registration
<i>NOW</i>	N/A	- 4 intensities + no headache - medication intake	- 3x initiate interactions per day

### 3.2 Analyse Phase

The findings from the exploration phase, revealed that existing headache diary apps, including Brain Twin, struggle to address patients' challenges and cognitive difficulties during headache episodes, complicating information registration and recall. User interviews, literature reviews, and app evaluations identified a key issue: the complex and time-consuming registration processes in current apps, which pose a burden, particularly during a headache. Notably, one of the apps had very few features, but received a high satisfaction score nonetheless, possibly implying user appreciation for simplicity and ease-of-use over extensive features.

In the context of headache patients, their medical condition and daily routines are critical considerations. Headaches can significantly impair the ability to use a diary app, often resulting in missed entries and retrospective reporting. To reflect this unique context, a *user journey* was designed, highlighting patients' mental state and emotional attitude towards headache logging. This journey reveals the onset of a headache as a time of physical discomfort and prioritisation of pain management over app logging. Furthermore, when accessing the app amidst pain, users may experience resentment or frustration, recognising the necessity for medical tracking but feeling the intrusion of the app as a constant reminder of their condition.

Our analysis indicated that headache diary apps could be improved by simplifying the registration process, enhancing reminder systems, improving data vi-

sualisation, and including an accessible feature for logging days without headaches. Among these potential improvements, we specifically chose to focus on refining interaction-related aspects that emerged as particularly impactful. In our redesign, we concentrated on headache intensity and medication intake as the primary information needs, as these were consistently featured across all apps and prominently in Brain Twin. This focus included tailoring the registration process to better accommodate individuals experiencing headaches and the cognitive challenges associated with them. The following design challenges (DC) were identified to steer the redesign process:

- *DC 1: Timely and accurate logging:* Design elements that encourage users to log their headache, or absence thereof, promptly and accurately, minimising delays and data entry errors.
- *DC 2: Facilitating easy information logging for people with headaches:* Design interactions that simplify registering headache information, considering the cognitive and physical challenges faced by individuals with headaches.

### 3.3 Align & Design Phase

In the align & design phase we addressed the challenges of timely, accurate logging and easy logging for people experiencing headaches. The goal was to create a method that enables swift entries and encourages logging, even in the absence of a headache. We identified a solution in NOW Interactions (Barendregt and Wasson, 2022), a novel mobile communication



Figure 2: Two NOW Interactions.

technique, utilising interactive notifications on Android devices. This approach minimises interaction time and effort by allowing users to respond directly within the notification, eliminating the need to open the app. For instance, users see the notification, simply tap their answer, and can go on with their day.

In the prototype, we implemented two NOW Interactions, designed and refined through iterative prototyping, self-testing, usability tests, and feedback interviews. The first interaction inquires about headache presence and severity, while the second interaction, prompted instantly upon an answer to the first, inquires about medication intake (see Figure 2). This approach merges the reminder and reporting steps, streamlining headache diary entries. Users can quickly log headache intensity and medication in just two interactions, bypassing the need to open an app. Iterations focused on optimising question content, wording, and response formats, ensuring clarity, conciseness, and medical relevance of the responses.

Alongside the NOW Interactions, a monthly diary view was added to the app to provide meaningful feedback on logged data (see Figure 3). It visually distinguishes 'no headache' days (green circles) from days without entries and shows the count of answered NOW Interactions per day, with an icon for the most severe headache. This calendar view offers an at-a-glance overview of monthly headache patterns.

While the prototype focused on optimising interactions, further enhancements could include more in-app functionality. There is also a need to log headaches through in-app interactions similar to the NOW Interactions. Our examination of other apps showed interesting data visualisations like pie charts and calendar views. Effectively presenting data to both users and clinicians remains key and should be studied systematically in future research to advance headache diary design.

### 3.4 Evaluation Phase

We conducted a user study with six participants to assess our prototype's acceptance and efficacy<sup>2</sup>. Over two weeks, they used the NOW Interactions headache diary, receiving three daily inquiries and additional inquiries after indicated headaches. This resulted in participants being sent between 42 and 84 NOW Interactions, totalling 330 inquiries sent, with a 78% response rate (262 responses). One participant dropped out after six days without logging headaches. The remaining five completed the study, averaging 49 entries each. Participants consistently used the prototype, with only one day where a participant did not log any entry, indicating high engagement.

Participants' expressed satisfaction with the redesign, appreciating the more streamlined data entry process compared to traditional apps. The expert user highlighted the convenience of not having to open an app for each log, a key feature of NOW Interactions. Reinforcing this positive response, the consulted neurology professor emphasised that incorporating NOW Interactions into traditional headache diaries addresses the need for quick logging. This is particularly beneficial for chronic pain conditions where simplified information registration is essential.

Usability inspections showed that the redesigned headache diary significantly reduced the number of interactions and time required to report a headache, indicating a lower respondent burden. The prototype allows headache intensity and medication intake logging with just two taps in interactive push notifica-

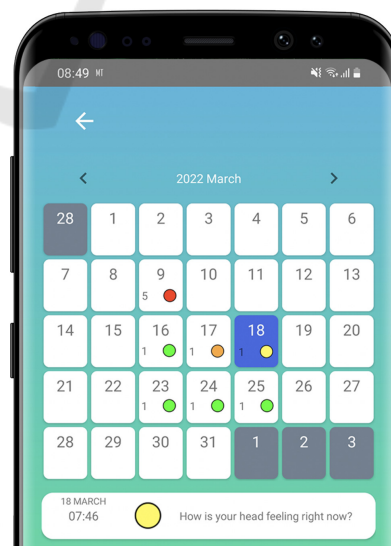


Figure 3: Diary view.

<sup>2</sup>More details of this user study can be found in (Barendregt et al., in press).

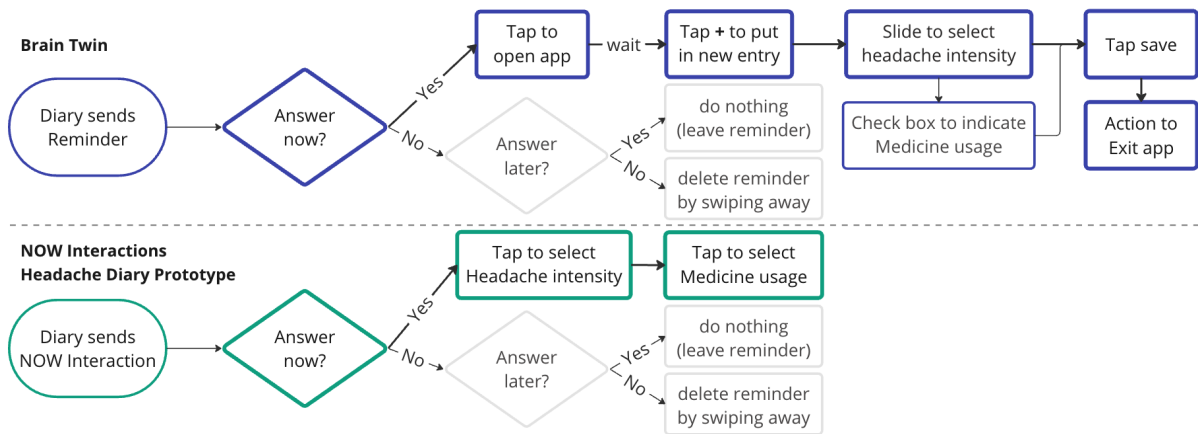


Figure 4: Comparison of processes to register a diary entry.

tions, bypassing app opening. In comparison, other apps need 5 to 19 interactions for similar data logging (see Table 1). Brain Twin, requires multiple steps including app launch and slider use for pain intensity, taking an estimated 15 seconds, compared to approximately 4 seconds with NOW Interactions. The main time-consuming elements in Brain Twin involved navigating to the log page and using the slider (see Figure 4).

### 3.5 Summary of Key Findings

By applying the RxD framework, we gained actionable insights to improve headache tracking.

*Explore phase:* We discovered that headaches affect cognitive abilities, including retrospective responses. All apps analysed, including Brain Twin, featured headache intensity and medication intake. User and expert feedback highlighted challenges in consistent logging and affirmed clinical relevance.

*Analyse phase:* We found that existing registration processes were inconvenient, particularly during cognitive impairment from headaches. This led to identifying two design challenges: ensuring timely, accurate logging, and simplifying the process for users.

*Align & Design phase:* Addressing these challenges, our redesign incorporated NOW Interactions to optimise diary entry time and effort, reduce number of interactions, and offer timely reminders. This enables immediate logging of headaches or the absence thereof, minimising retrospective errors and enhancing the overall user experience.

*Evaluation phase:* Participants used the NOW Interactions prototype over two weeks, responding to 78% of 330 inquiries. The streamlined process required just two taps without opening the app, easing immediate logging and improving respondent burden and data quality by promoting real-time over retro-

spective reporting. Participants appreciated the simplicity, indicating satisfaction with this approach.

## 4 DISCUSSION

Headache diaries are crucial for diagnosing and managing headaches, yet research on their design and its effect on respondent burden is limited. This paper shows how using the RxD framework, a valuable tool for individuals designing self-report tools to consider patient context, can refine interactions in existing applications, reducing respondent burden and enhancing user experience without compromising clinical integrity. While initiating a design from scratch presents fresh perspectives, redesigning an existing app like Brain Twin, collaboratively developed with headache specialists, is more time-efficient. It allows for a quicker identification of improvement areas while ensuring clinical needs are already met.

The RxD framework inherently incorporates the clinical perspective, yet this project primarily emphasised the respondent's viewpoint. Acknowledging the importance of the clinical aspect remains essential for comprehensive diary design (Hundert et al., 2014). Collaboration with clinical experts does not always guarantee effective communication of clinical needs to developers. Had we initiated this project from scratch using RxD, our insights could have differed, possibly affecting the user interface and shifting clinical focus. Future research could explore developing a headache diary from the ground up using RxD, potentially revealing new insights to enhance both user experience and clinical relevance.

Using the RxD framework allowed us to identify unique user needs, pinpoint design challenges, and conceptualise solutions like NOW Interactions that directly address these challenges. This study high-

lights the value of the RxD framework in developing health applications and suggests potential for its wider application in this field. As technology evolves novel solutions are needed to facilitate patient's active involvement in their healthcare. RxD can play a central role in finding such approaches that align with patient needs.

Our headache diary prototype, redesigned using the RxD framework and incorporating NOW Interactions, received positive feedback, indicating its potential to integrate with or complement existing headache diary apps. With 5-10 users often revealing most usability issues (Nielsen, 2012), our six participant usability study provided valuable feedback for interface improvements, despite not confirming clinical validity. Larger studies, including clinical validity evaluations, are necessary for comprehensive validation. Our usability study is a preliminary step towards this, aiming to refine user interface and interactions with individuals sharing similar traits to our target users before advancing to clinical trials, thereby enhancing future trial reliability and minimising patient inconvenience. Future research should also explore personalisation in self-report and NOW Interactions to meet individual patient circumstances and needs, potentially balancing simplicity and utility. Adjustments in interaction timing and presentation, the nature of requested data, and data presentation and display can reduce perceived respondent burden and enhance relevance for both patients and healthcare professionals. The data in Table 1 reveals that both the simplest app and the most feature-rich app received high user satisfaction scores. This could imply the need for a balance between simplicity and utility. Future research should investigate how both offering minimalist logging mechanisms, such as NOW Interactions, and extensive in-app features can provide users with the flexibility to choose based on their immediate needs and conditions.

## 5 CONCLUSION

In this paper, we demonstrated the value of the RxD framework in the context of redesigning a headache diary. By adhering to the framework, we were able to understand the unique user context, notably the pain and discomfort that directly impacts cognitive abilities. We identified the critical needs of the diary to include timely and accurate information logging and a simple information retrieval process. In response to these identified needs, we proposed a design solution using NOW Interactions. This solution allows for seamless headache logging without the need to open

an app, a design choice aiming to minimise the cognitive load on individuals suffering from headaches.

Evaluations showed users appreciated the reduced necessity to open an app for every data log. This perspective was reinforced by a neurologist, who emphasised the importance of simplifying the data registration process for patients. Compared to existing solutions, the NOW Interactions solution has cut down necessary interactions by over 50%. The results suggest NOW Interactions can alleviate respondent burden and enhance data quality by promoting timely interactions and streamlining information retrieval.

The research showed the potential of the RxD framework and innovative interactions to enhance user experience in medical self-report diaries, with the overarching goal of reducing respondent burden. Future research could explore using the RxD framework to design a headache diary from the ground up, building upon the insights from this research to push the boundaries of patient-centric innovation.

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