

The development of an electronic motor symptoms diary for Parkinson's disease using qualitative patient insights

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BACKGROUND

The Hauser diary [1] is a valuable tool to assess motor fluctuations in Parkinson's disease (PD) subjects. It involves intensive use, requiring patients to record for each 30-min segment of the waking day: when medication is thought to be providing motor fluctuation benefits; when such effects have worn off, and when dyskinesias are experienced. The diary is recommended for self-completion at home over 2–4-day intervals, periodically within a clinical trial.

Pen-and-paper completion poses questions about data integrity and quality as timely completion cannot be assured. Recall over time may also be inaccurate and the fine motor skills required in its completion may be challenging at times for subjects with PD [2].

METHODS

Usability study



10 Parkinson's disease Patients



Recruited through Parkinson's UK



1 Site



UK

- An electronic version (tablet/smartphone) of the Hauser diary was developed, focusing on ease of use for PD patients.
- 10 subjects with PD were recruited in the United Kingdom through Parkinson's UK and qualitative semi-structured interview were conducted to investigate the usability of the solution and guide iterative design decisions.

RESULTS

Table 1: Usability Testing – Main findings

ITEM	FINDING
Stylus vs. finger	Easy to navigate the device with fingers. The stylus proved to be extremely unpopular.
Alarm sounds	Subjects liked the concept of being able to select their own alarm sound from options available. The sound of “Birds” chirping was the most popular option.
Layout and navigation	General layout of the e-Diary and the font sizes received extremely positive feedback; subjects found it easy to navigate the device after some training.
Paper vs. electronic	The use of an electronic device for PROs was the preferred choice not only for the subjects but also their caregivers .
Security	Subjects were particularly impressed that they had the option of a personal PIN code which only they had access to.
General usability	The subjects indicated that they were more likely to want to use a mobile device compared to paper if they were taking part in a clinical trial. Most subjects reported no concerns about having to fill in the eDiary every 30 minutes for up to three days before a clinic visit.
Recall period	Subjects generally agreed that, if they had a mobile device with regular alarms to record their data, they were more likely to accurately record their ON/OFF period and other symptoms. With a paper questionnaire, they would be tempted to fill it in once a day.

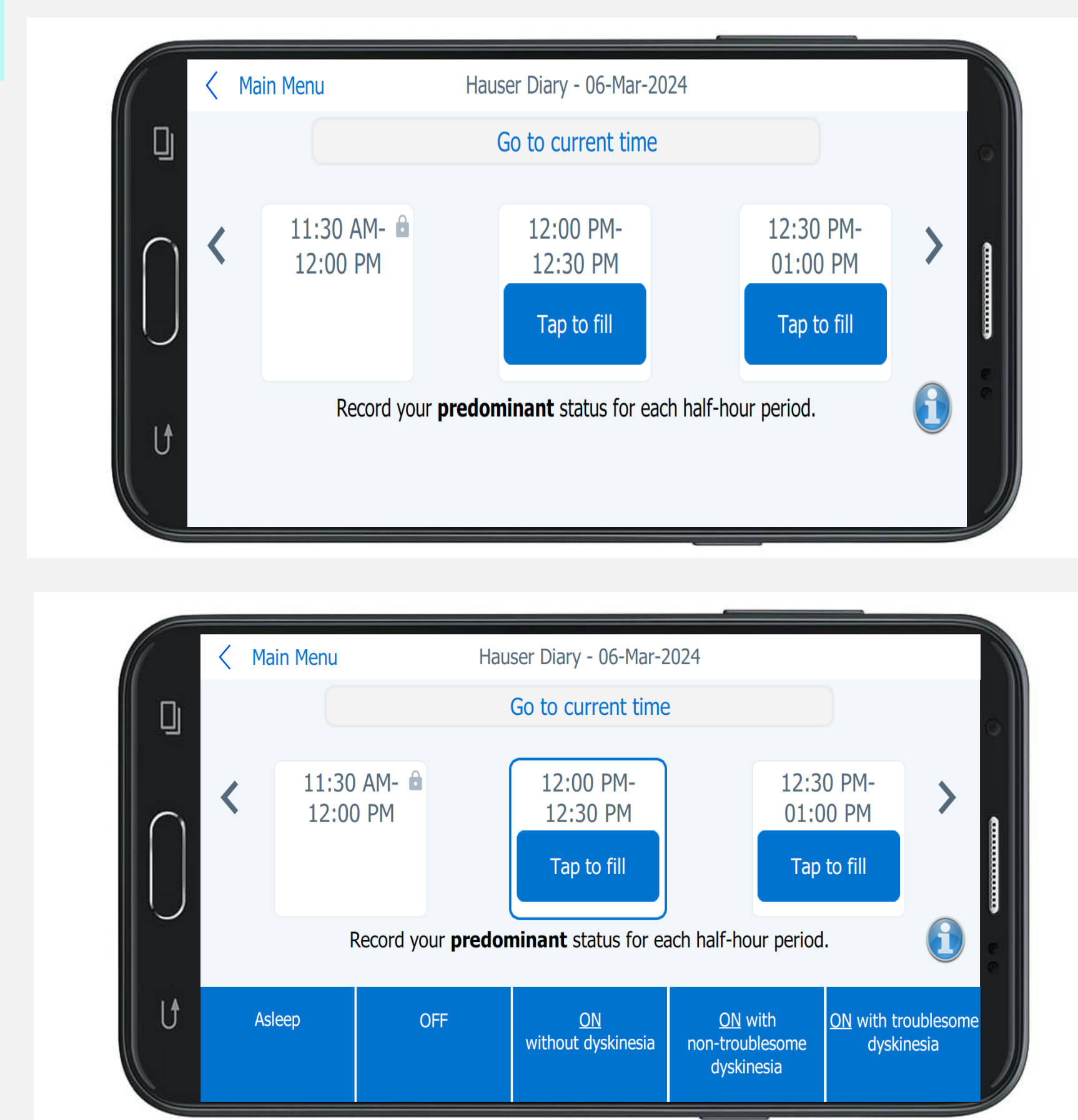


Figure 1. Electronic version of PD diary on mobile device

Patients with tremor and small joint issues indicated preference for:

- Knuckle** for touchscreen actions instead of fingertip or stylus
- e-Diary “**touch areas**”: need for reliably accept feedback from the knuckles
- e-Diary **components: large and separated** sufficiently

Design principles established:

- Landscape** format
- Scrollable** daily record format
- Single 30-min interval** per screen

PD subjects' feedback:

“An eDiary would be my preferred method to use. The layout is nice and I like the bird alarm [completion reminder]. I might get a man bag to carry it.”

The eDiary is definitely better than scribbling on a piece of paper. I can see myself using it.”

CONCLUSION

- Collecting patient-reported outcomes data electronically is valuable in addressing the known limitations of paper collection [3].
- Good usability of electronic solutions is vital to ensure ongoing completion.
- This study provides initial positive feedback on the design and usability of an electronic version of the Hauser diary in subjects with Parkinson's disease.

REFERENCES

- [1] Hauser RA, Friedlander J, Zesiewicz TA et al. A home diary to assess functional status in patients with Parkinson's disease with motor fluctuations and dyskinesia. Clin Neuropharmacol. 2000; 23: 75-81.
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