

# The Use of Electronic Sleep and Symptom Diaries: A Feasibility Study

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## Background

- Multiple sclerosis (MS), is an auto-immune disease that affect the central nervous system and afflicts over 400,000 people in the U.S.
- Patients suffer from a wide range of symptoms including sleep problems, pain, and fatigue.
- Consequences of chronic sleep problems, pain and fatigue include heart disease, stroke, cognitive decline, and accidents.
- Electronic diaries (ED) can effectively track symptoms if there is feasibility and acceptance from persons with MS (pwMS).
- Capturing self-report symptoms electronically in real-time is an innovative method that will provide the most up-to-date information impacting patient care for MS.

## Objectives

- The **overall objective** in this pilot, mixed method, descriptive, repeated measures study was to test feasibility and acceptability of electronic sleep and symptom diaries delivered using an email message link to measure the acceptability and ease of use.
- We also examined participant demographics as related to submission compliance.

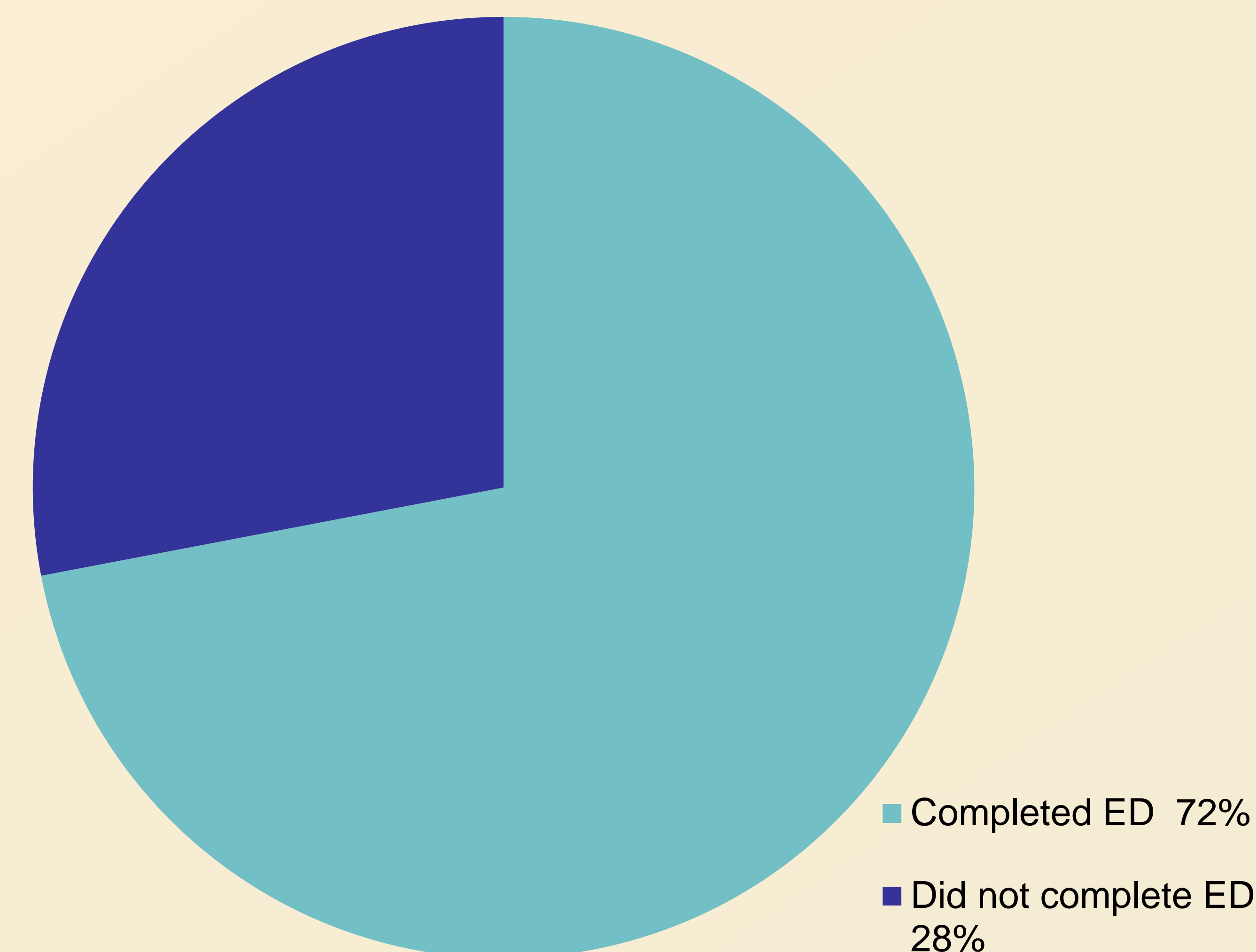
## Method

- Inclusion criteria consisted of knowledge of computer, internet, and English Language.
- During the baseline visit, a set of questionnaires was administered to collect information about demographics, sleep, and depression.
- The participants were asked to use EDs daily over the course of seven consecutive days, which was repeated eight weeks later.
- The link to the ED was sent via REDCAP data capture program using a semi-structured qualitative patient diary, as well as the SR-EDSS, a Sleep Visual Analogue Scale, MS-RS, and Sleep Behavior Checklist.
- Six participants participated in focus groups to discuss the acceptability and ease of use of the EDs.
- Statistical analyses were performed using SAS version 9.4.

## Sample Characteristics

- This convenience sample of pwMS included relapsing-remitting (RRMS) MS and secondary progressive (SPMS) MS.
- **36** total participants were originally enrolled in the study, with **26** completed the EDs.
- The majority (88%) of participants were women with a mean age of 46 and EDSS score of 3.8 (SD 1.8).
- The mean time since diagnosis in years was 12 (SD = 7.4).
- Approximately 8% of participants had SPMS.

Figure 1 – Compliance with Completing ED



## Results

- Participants were compliant with diary completion over the entire eight study weeks with 72% of diaries completed.
- Participants who completed the study found the methodology to be acceptable, enjoyed and felt comfortable participating in the study.
- Submission rate did not differ across age, gender or MS subtype.
- There was a trend toward submission difference related to higher education level.

## Comments on Acceptability from Focus Groups

- Participant comments were *“I think it’s easy online, it’s very simple. I didn’t have any trouble.”*
- Another participant stated *“I liked it because it did help me track my sleep schedule . . . I didn’t realize, I mean I knew I was having sleeping problems but I didn’t really realize it until I saw it in front of me.”*
- Acceptability was particularly illustrated by this comment: *“I think it was very easy to fill it out online, and I also liked the fact that you gave us a box, that if we wanted to expand on what we were saying, that was a good idea, because just one question doesn’t always give you the information that you need and we were able to give you a little bit more, be more informative about what was going on with us. I liked that part.”*

## Conclusions

- These findings provide preliminary evidence for the use of EDs as a symptom data collection for pwMS.
- Tailoring this technology to patient needs and preferences may improve its acceptance by pwMS.

## Disclosures

- Drs. Newland, Riley, Lorenz, and Ms. Mary Bordner have no disclosures to report.

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