# “Please complete your surveys”: a targeted review of adherence rates in real-world studies using digital technologies

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## Background & Objectives

Longitudinal observational studies play a central role in advancing understanding of the onset and progression of physical and mental health conditions in the real world[1] and help with extrapolating data obtained in randomized controlled trials[2]. However, poor adherence to data capture activities can reduce the generalizability of outcomes and the statistical power to detect effects of interest.

As the use of digital technologies increases, researchers are able to gather data from patients using online surveys and questionnaires accessible through mobile phones and computers. However, some data show that these digital studies can be affected by poor participant adherence[3].

This review aimed to assess participant adherence rates in real-world studies, with a focus on those using digital technologies.

## Methods

Study publications (published in the last 10 years) were identified through targeted searches of the PubMed database and Google Scholar. Publications were assessed for availability of information on adherence rates and, where appropriate, details of incentives offered to participants.

## Results

Fourteen studies were included in the review (see **Table 1**).

The data show that adherence rates to data capture activities vary considerably. Among studies with daily data collection (n=9), where total data collection periods ranged from 7 days to 141 days, adherence to data capture activities ranged from 9% to 96%.

Among studies with weekly data collection (n=2), where total data collection periods ranged from 4 weeks to 2.5 years, adherence ranged from 63% to 84%.

Among studies with less frequent data collection (ranging from every 3 months to yearly, n=3), where total data collection periods ranged from 1 to 4.5 years, adherence by the end of the study ranged from 1% to 38%.

Six studies reported offering participants incentives for completion of data capture activities. None of these studies explored whether incentives impacted adherence to data capture activities.

*Table 1 Overview of studies included in this review*

| Author(s) | Study participants | Study location | Data collection period | Data collection frequency | Key finding(s) on adherence to data collection activities |
|---|---|---|---|---|---|
| Artinian et al. (2003) | Patients with congestive heart failure | USA | 3 months | Daily | 85% of participants completed daily weight monitoring and 81% of participants completed blood pressure monitoring activities |
| Cormack et al. (2019) | Patients with mild-to-moderate depression | UK | 6 weeks | Daily | A mean 96% of participants completed the daily cognitive assessment across the 6-week period |
| Di Fraia et al. (2020) | Patients with seasonal allergic rhinitis | Italy | 7 weeks | Daily | Mean adherence during the final phase of the study (approximately day 47+) was 79% |
| McConnell et al. (2017) | Members of the general public | USA | 7 days | Daily | 9% of participants completed all 7 days of data collection |
| Paramore et al. (2021) | Patients with transfusion-dependent beta-thalassemia + caregivers | Italy<br>UK<br>USA | 90 days | Daily | 45% of participants responded to the daily patient-reported outcome instruments |
| Rudell et al. (2016) | Multiple sclerosis patients + clinicians using the app to interact with patients | USA | Not defined | Daily | 31% of participants in the study used the app daily |
| Weerts et al. (2020) | Patients with irritable bowel syndrome | The Netherlands | 70 days | Daily | 88% mean completion rate of the daily digital symptom diary during all 70 days of study duration |
| Weisel et al. (2014) | Patients with asthma | USA | 27–141 days | Daily | 52% of participants completed the daily questionnaire on 90%+ of their time in the study<br>72% of participants completed the daily questionnaire on 80%+ of their time in the study<br>100% exceeded 50% of the eligible days |
| Xu et al. (2018) | Members of the general public | USA | 4 weeks | Daily | 68% of participants completed all 28 questionnaires |
| Amorim et al. (2021) | Emergency department patients with lower back pain | Australia | 4 weeks | Weekly (weeks 1, 2, and 4) | Out of 51.5% of participants who completed the week 1 survey, 84% completed the final week 4 survey |
| Barber et al. (2016) | 18- and 19-year-old women from the general public | USA | 2.5 years | Weekly | Adherence to completing the weekly survey at 2.5 years was 63% |
| Pathiravasan et al. (2021) | Members of the general public | USA | 1 year | Every 3 months | Only 1% of participants completed data capture activities 12 months into the study |
| Lee et al. (2018) | Patients with myasthenia gravis | USA | 4.5 years | Biannual survey | 21% response rate for the 9th follow-up biannual survey on prednisone steroid use |
| Loxton et al. (2019) | Young women born between 1989 and 1995 | Australia | 3 years | Yearly | All 3 follow-up surveys were completed by 38.21% of women |

## Discussion & Conclusions

Real-world research is crucial to creating a broad picture of a disease or research area[2]. To draw robust, generalizable conclusions from real-world studies, participant adherence to data capture activities is vital. It is therefore important to understand what factors may affect adherence, to inform the design of future studies.

In this targeted review, no trend was observed to indicate that adherence was dependent on specific factors, including data collection frequency, study duration, or location. However, the number of studies reviewed here might not have been large enough to draw robust conclusions. A systematic review or meta-analysis may help to further explore whether specific study characteristics impact adherence rates.

Future research could also focus on a detailed investigation of the relationship between incentives and adherence to data capture activities.

## References

[1] Taur SR. Perspect Clin Res 2022;13(1):12–16.
[2] Katkade VB et al. J Multidiscip Healthc 2018;11:295–304.
[3] Pratap A et al. NPJ Digit Med 2020;3:21.
Additional references available upon request.

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