

# Empowering Patients in Observational Research: Leveraging Data Insights for Sustained Engagement and Innovation

Clara C. Hancock, Ashley N. Cogell, Brittany L. Dreier, Megan K. Belden, Haley S. Friedler, Erin M. Smith



## Background & Purpose

### Background

Real-world evidence (RWE) is essential in drug development, yet patient engagement in observational studies remains challenging:

- Most patients (85%) want access to their medical data and study results.
- 73% expect results to be returned in their preferred language and format (Getz et al, 2025).

### Purpose

This study explores how returning research insights to participants ("sharebacks") influences engagement and participation in research.

## Methods

- Participants accessed their medical records and research insights via the PicnicHealth platform.
- Three patient-facing research summary campaigns ("sharebacks") were evaluated across multiple sclerosis (MS), Huntington's disease (HD), and early breast cancer (eBC) cohorts, along with two caregiver-facing sharebacks for Alzheimer's disease and a disease-agnostic group.
- Campaigns varied in:
  - Delivery format (e.g., content type, opt-in status, monthly product emails)
  - Content type (e.g., data dashboards, visualizations, summaries)
- Engagement metrics—including survey completion (SC), email open rate (EOR), and summary click rate (SCR)—were analyzed.
- Qualitative interviews were conducted with HD participants to explore perceptions of the shareback experience.

Table 1. Shareback campaigns.

Cohort	Type	Shareback Delivery Type	Total Emails Sent	Open Rate (EOR)	Click Rate (SCR)
Alzheimer's Disease	Click to See Results	Interactive Dashboard	122	68.9%	34.4%
Alzheimer's Disease	Share Your Data to See Your Data	Interactive Dashboard	370	31.3%	1.9%
Alzheimer's Disease	Share Your Data to See Your Data - Reminder	Interactive Dashboard	328	23.7%	2.6%
Multiple Sclerosis	Share Your Data to See Your Data	Interactive Dashboard	3425	28.2%	2.9%
Multiple Sclerosis	Share Your Data to See Your Data - Reminder	Interactive Dashboard	2637	29.6%	3.0%
Huntington's Disease	Opt-In to See Results	Static PDF	444	49.1%	22.4%
Huntington's Disease	Attached Results in PDF	Static PDF	95	83.3%	51.6%
Early Breast Cancer	See Results on Research Dashboard	Static PDF Delivered In-app	4993	37.7%	6.5%
Early Breast Cancer	See Results on Research Dashboard - Reminder	Static PDF Delivered In-app	4842	35.0%	4.3%
Early Breast Cancer	See Results on Research Dashboard (Wave 2)	Static PDF Delivered In-app	405	30.9%	3.7%
Early Breast Cancer	See Results on Research Dashboard (Wave 2) - Reminder	Static PDF Delivered In-app	404	30.1%	3.5%

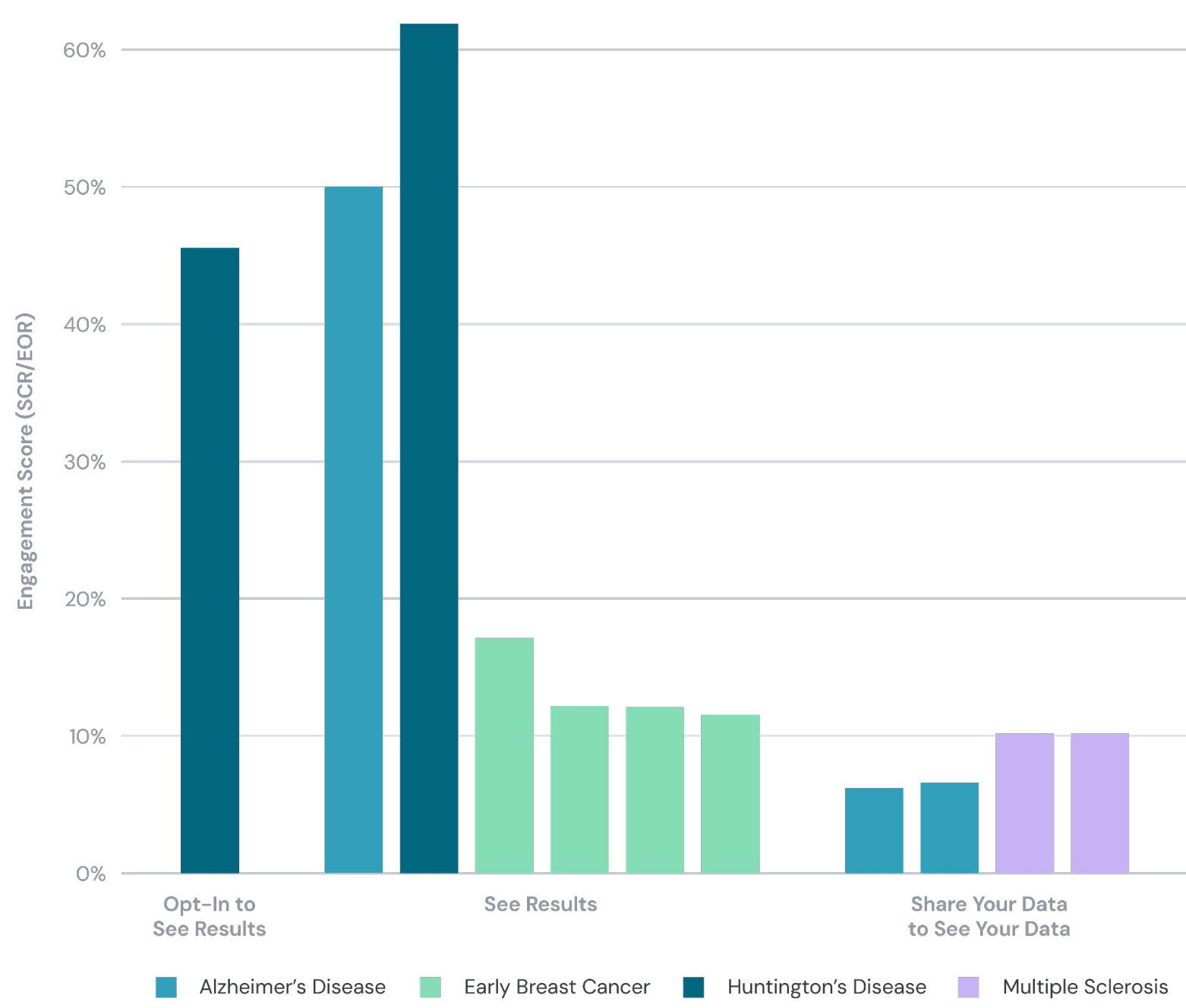


Figure 1. Comparative Engagement Metrics Across Campaigns. Engagement rate (SCR/EOR) was generally higher for "See Results" campaigns, suggesting that returning meaningful insights without additional requests (such as completing a survey) may foster stronger engagement.

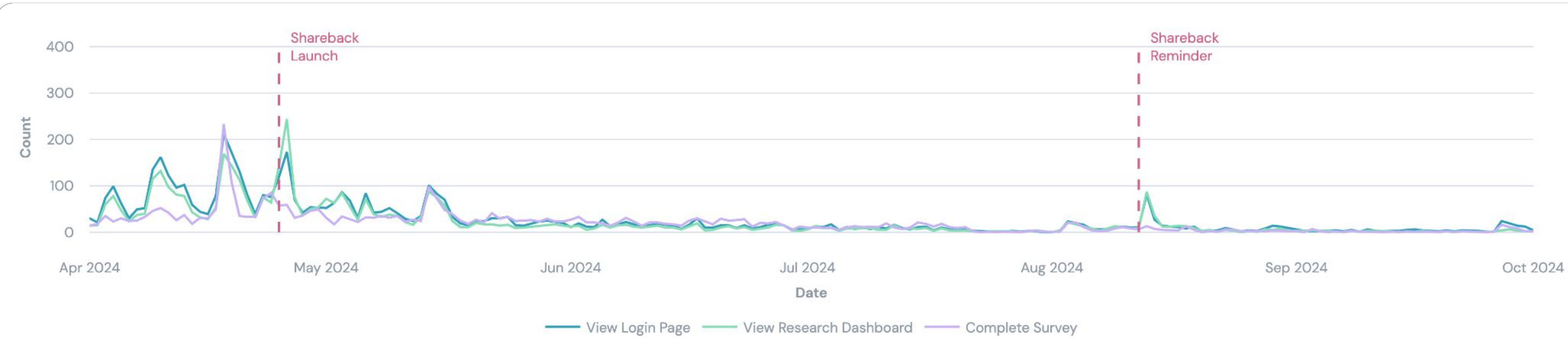


Figure 2. Engagement Metrics Following "See Results" Shareback in the eBC Cohort. A Social Determinants of Health (SDoH) shareback was shared with the early Breast Cancer (eBC) community via the PicnicHealth Research Dashboard. During the days following two shareback-related emails, unique user logins and research dashboard views spiked (blue and mint, respectively), while survey completions (purple) were unaltered, suggesting that while participants engaged with the data, they were less likely to complete new surveys without a direct prompt.

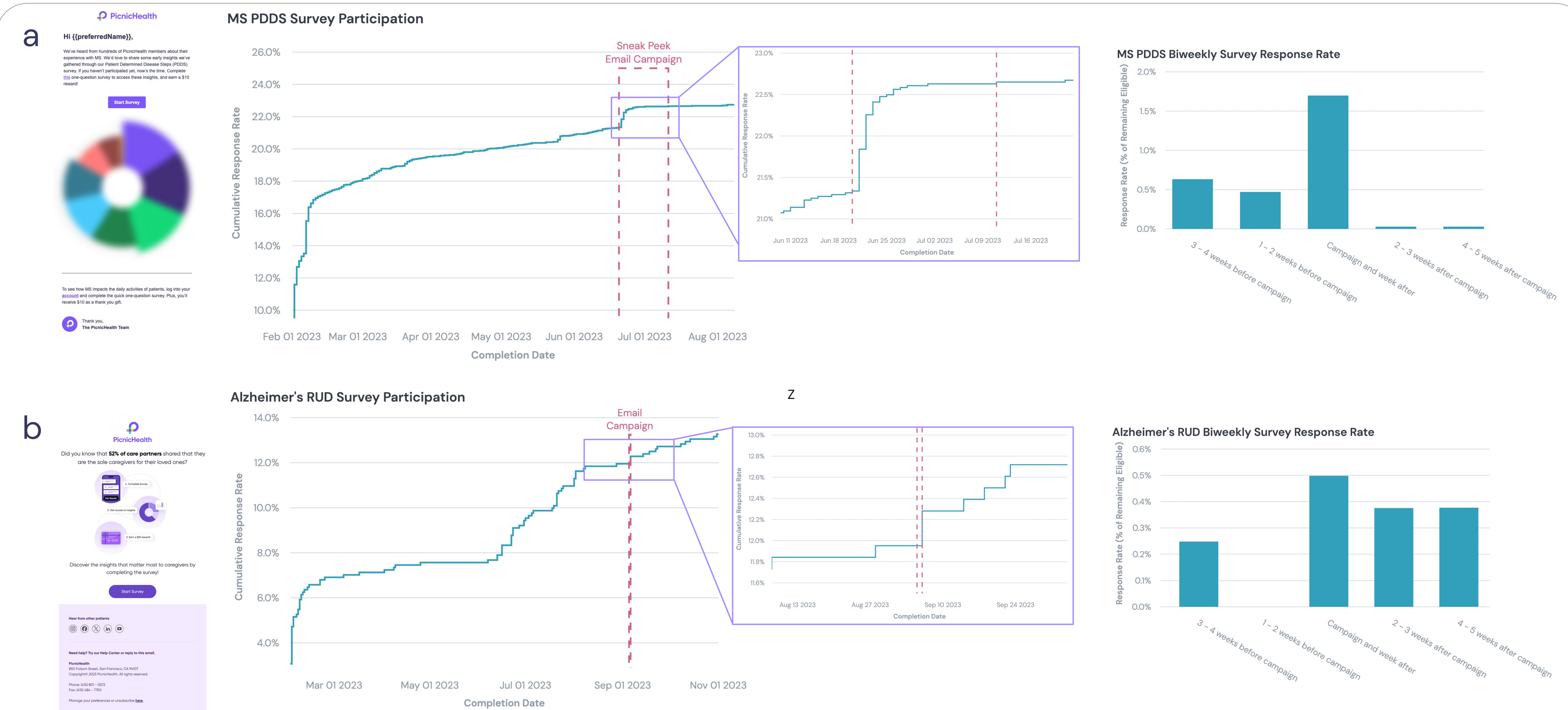


Figure 3. Survey Completions Following "Share Your Data to See Your Data" Campaigns. Email campaigns with a call-to-action to complete a survey in exchange for personalized insights led to increased survey completions in two cohorts. In the Multiple Sclerosis (MS) group, completions rose 3.6–16-fold (7 before vs. 61 during and after the campaign). Among Alzheimer's caregivers, the Resource Utilization in Dementia (RUD) survey completions increased fivefold (2 before vs. 10 during and after). The largest response spikes occurred within two days of email delivery.

## Results

### Shareback Strategies and Engagement Outcomes

Different shareback approaches (Table 1) led to measurable differences in patient engagement. Campaigns that featured interactive visuals and clearly communicated value were more likely to drive participant actions such as completing surveys and interacting with the app. Engagement was shaped by content type, call-to-action clarity, and delivery method.

### "See Results" Campaign

This strategy emphasized sharing research insights without requesting additional input from participants. It significantly increased app logins and dashboard interactions (Figure 2; blue and mint lines), but did not meaningfully impact survey response rates (purple line).

### "Share Your Data to See Your Data" Campaign

These campaigns included a direct call-to-action encouraging participants to complete a survey in exchange for personalized data. This approach resulted in substantial increases in survey participation:

- MS participants: 3.6x increase (Figure 3a)
- Alzheimer's caregivers: 5x increase (Figure 3b)

The highest response rates occurred within 48 hours of the email being sent.

### Monthly Product Emails

Caregiver-focused sharebacks embedded in monthly product emails had a modest 4% survey completion rate (data not shown). Despite the lower response rate, qualitative feedback was largely positive—participants valued receiving updates and expressed interest in more detailed sharebacks.

## Conclusion

Returning research insights increases engagement and supports participant-centered research design. In addition to demonstrating the value of sharebacks, our findings highlight the importance of timing and framing in driving action.

- Larger, passive engagement can be achieved with appealing content alone
- Meaningful participation requires clear value exchange and calls-to-action
- Qualitative feedback suggests non-respondents may still find value in receiving results

Future campaigns should:

- Tailor content to study interests and needs
- Deliver easy-to-understand visual content
- Include direct calls-to-action
- Test delivery channels and formats more directly

## Acknowledgements

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## Disclosures

Authors are employees of PicnicHealth