

# Understanding Patient Underreporting of MS Relapses: Insights From a 2017 Survey of Patients With Multiple Sclerosis

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# **BACKGROUND**

- Approximately 37% of patients experience multiple sclerosis (MS) relapse while on a disease-modifying therapy (DMT)1\*
- On average, patients on a DMT will experience 1 relapse every 3 years<sup>1\*</sup>
- Incomplete recovery from acute relapses can lead to rapid accumulation of disability<sup>2-7</sup>
- It is important that patients identify and report symptoms of relapse so that physicians can appropriately treat with the goal of maximal recovery
- There is limited understanding of which patients do not report symptoms of MS relapse and the drivers of this behavior

Based on registration trials of all DMTs currently on the market (as of December 1, 2016) save for Novantrone.1 <sup>†</sup>During the trial periods, which ranged from 48 weeks to 108 weeks.1

### **OBJECTIVES**

- Determine the proportion of patients with MS who don't consistently report symptoms of relapse
- Identify why patients don't consistently report symptoms of relapse

# **METHODS**

# Study design

- The survey was administered online by Harris Poll between March 14, 2017 and April 4, 2017 on behalf of Mallinckrodt Pharmaceuticals
- A total of 250 adults ≥18 years old who had been diagnosed with MS and had a relapse within the past 3 years ("patients") were included; patients were recruited to participate from online panels
- Behaviors and beliefs associated with "always" and "not always" (rarely/sometimes/ never) contacting the physician upon suspicion of a relapse were recorded
- To align with actual proportions in the population, data were weighted for gender by age, region, race/ethnicity, education, and income where necessary

# Statistical analyses

- Between-group differences were analyzed using a standard t test at a 95% CI (P<0.05)

# **RESULTS**

# PATIENT DEMOGRAPHICS

Characteristic	N=250
Mean age, years	47.1
Gender, %	
Male	35
Female	65
Mean years since MS diagnosis	10.9
Type of MS, %	
Relapsing-remitting	79
Secondary progressive	10
Progressive-relapsing	8
Other	2
Not sure	1
Last confirmed MS relapse, %	
<6 months ago	22
6 months to <1 year ago	23
1 year to <2 years ago	37
2 years to <3 years ago	19
Currently treated with DMT, %	69

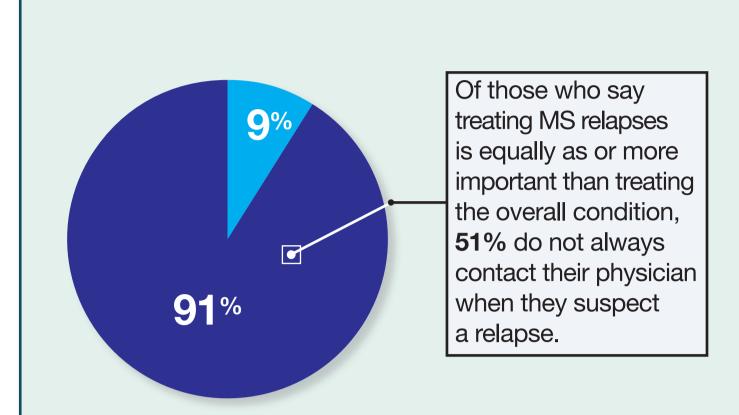
#### PATIENT REPORTED BEHAVIOR WHEN EXPERIENCING SYMPTOMS OF RELAPSE

 Approximately half of patients (51%) state that they do not always contact their physician when they suspect that they are experiencing a relapse



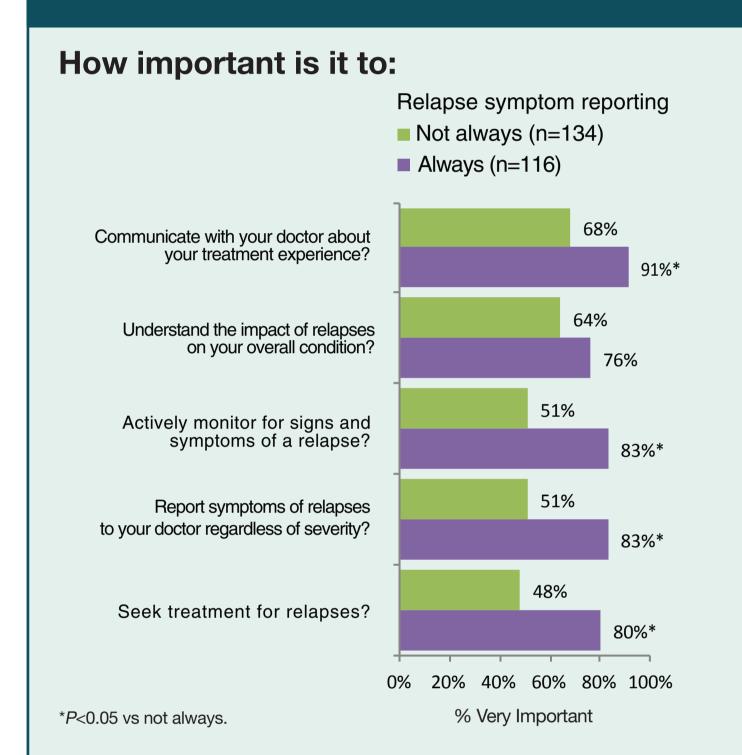
#### BELIEFS ABOUT THE IMPORTANCE OF TREATING RELAPSES VS TREATING OVERALL CONDITION

Treating relapses is less important than treating the condition Treating relapses is equally as or more important than treating



 Overall, 91% of patients agree that treating relapses is at least equally as important as, if not more important than, treating their overall condition

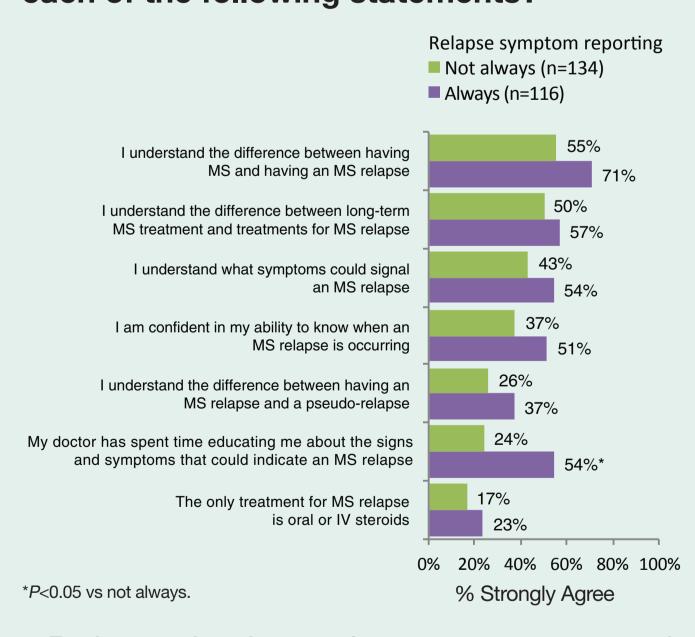
### **ACTIONS CONSIDERED TO BE** "VERY IMPORTANT" BY PATIENTS



 Patients who do not always report suspected symptoms of a relapse are significantly less likely than those who always report to say that it is very important to communicate with their doctor about treatment experience, actively monitor for signs and symptoms of a relapse, report symptoms of relapses to their doctor regardless of severity, and seek treatment for relapses

#### STATEMENTS ABOUT MS THAT PATIENTS "STRONGLY AGREE" WITH

How much do you agree or disagree with each of the following statements?



 Patients who do not always report suspected symptoms of a relapse are less likely to strongly agree that their physicians spend time educating them about signs and symptoms that could indicate an MS relapse

#### **ABILITY TO IDENTIFY COMMON INDICATORS OF RELAPSE**

	Relapse symptom reporting	
Number of correctly identified indicators of relapse, %	Always (n=116)	Not always (n=134)
4	6	16
3	41	26
2	31	28
1	15	23
0	8	8

• There were no significant differences in the understanding of common indicators of relapse by reporting behavior

3. Experiencing symptoms that are unrelated to a fever, illness, or other condition; 4. Symptoms that occur ≥30 days after a previous relapse.

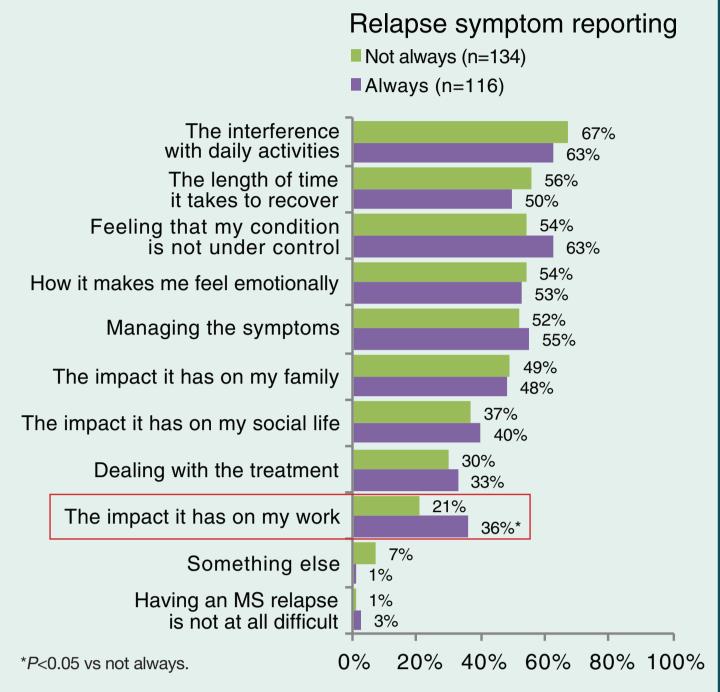
Correct indicators: 1. New or worsening symptoms; 2. Symptoms that last for >24 hours;

Incorrect indicators: 1. Symptoms that occur less than a week after a previous relapse; 2. Symptoms that resolve within a few hours

Patients were asked to identify all common indicators of a relapse.

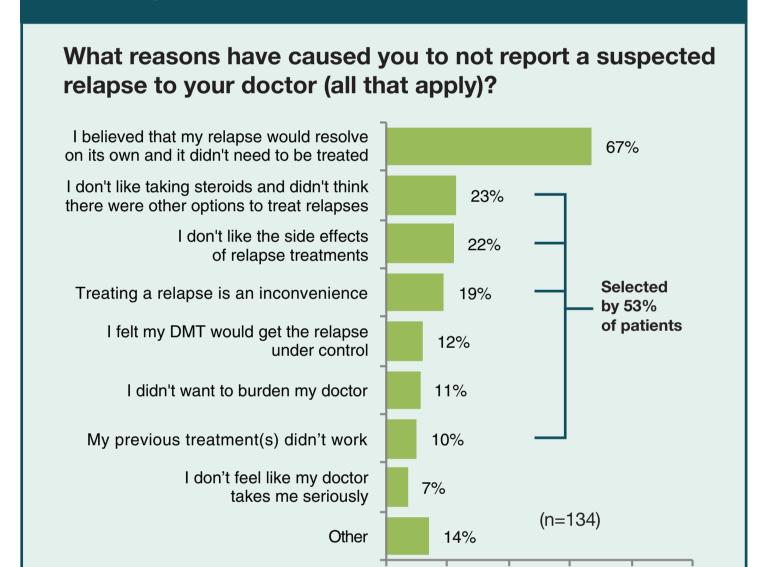
### MOST DIFFICULT ASPECTS OF LIFE WHEN EXPERIENCING AN MS RELAPSE

What are the most difficult parts of having an MS relapse (all that apply)?



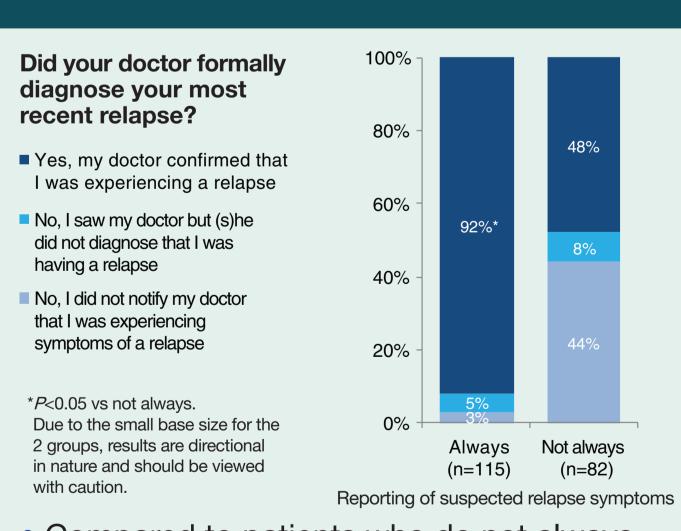
 Patients who do not always report suspected relapses are significantly less likely than those who always report to indicate that the impact on work is one of the most difficult parts of having a relapse

### **REASONS FOR NOT REPORTING** SUSPECTED RELAPSES AMONG PATIENTS WHO DO NOT ALWAYS **REPORT**



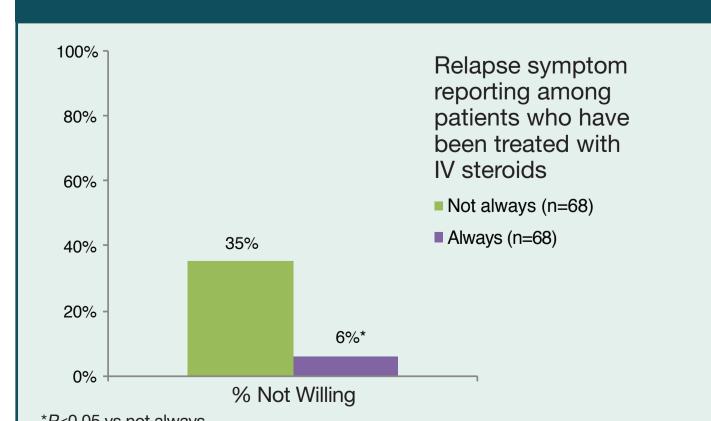
- Of patients who do not always report suspected relapse symptoms, over twothirds believed their relapse would resolve on its own and it didn't need to be treated
- 53 percent of these patients expressed some dissatisfaction with relapse therapy

#### **CLINICAL DIAGNOSIS OF MOST** RECENT RELAPSE AMONG PATIENTS WHO REPORTED SYMPTOMS TO THEIR PHYSICIAN



- Compared to patients who do not always report relapse symptoms, significantly more patients who always report their symptoms indicated that their doctor confirmed their most recent relapse
- When considering only patients who reported their most recent relapse symptoms to their doctor (Always, n=115; Not always, n=82), 14% of those who do not always report their relapses said their doctor did not confirm their relapse compared to 5% of those who always report their relapses

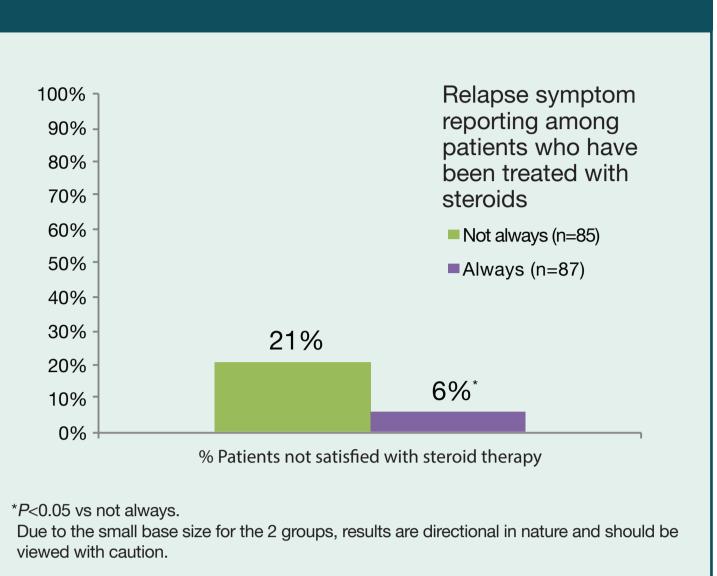
#### PATIENTS NOT WILLING TO BE TREATED AGAIN WITH IV STEROIDS



\*P<0.05 vs not always. Due to the small base size for the 2 groups, results are directional in nature and should be

 Among patients who have been treated with IV steroids, those who do not always report suspected relapses are more likely not willing to be treated again compared with those who always report suspected relapses

#### PATIENTS NOT SATISFIED WITH **STEROID THERAPY**



 Among patients who have been treated with steroids, those who do not always report suspected relapses are more likely to be dissatisfied with their steroid therapy compared with those who always report

# **SUMMARY AND** CONCLUSIONS

### Summary

- Approximately half of patients (51%) admit to not always contacting their physician when they suspect that they are experiencing a relapse
- While most patients believe it is at least equally as important to treat relapses as to treat their MS, half do not always report symptoms of relapse
- There is not a significant difference in the understanding of the indicators of relapse based on reporting pattern
- Patients who always reported suspected relapses are more likely than those who did not to - Say their doctor has spent time educating
  - them about relapses
  - State that it is important to monitor and report symptoms, and seek treatment
  - Be satisfied with prior steroid therapy and be willing to be treated again with IV steroids

# **Conclusions**

- Physicians may not be aware that some patients do not feel sufficiently educated about the signs and symptoms of relapse
- Physicians should consider increasing education reinforcing the need to report relapse symptoms and treatment experience - Incomplete recovery from acute relapses can
  - cause rapid accumulation of disability<sup>2-7</sup>
- As a best practice, patients should have a follow-up 1 month ± 1 week after relapse therapy. In addition to standard assessment scales, the patients' perception of symptoms and disability, as well as impressions about response to treatment, should be determined<sup>8</sup>
- Patients who are dissatisfied with prior relapse therapy may benefit from education about the availability of alternative therapies to encourage reporting of relapse symptoms
- Future surveys will aim to further delineate the impact of various factors on beliefs and reporting behavior such as severity of symptoms, type of relapse, proximity to medical care, and type of physician

# REFERENCES

- 1. Data calculations on file: Estimated ARR and percent patients relapsing based on registration trials of all DMTs currently on the market (as of Dec 1, 2016), save for Novantrone.
- 2. Gholipour T, et al. *Neurology*. 2011;76(23): 1996-2001.
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- 4. Scott TF, et al. J Neurol Sci. 2010;292(1-2):52-56. 5. Scott TF, et al. Mult Scler Relat Disord. 2016;5:1-6.
- 6. Leray E, et al. Brain. 2010;133(pt7):1900-1913.
- 7. Confavreux C, et al. *Brain*. 2003;126(pt4):770-782. 8. Ross AP, et al. Int J MS Care. 2012;14:148-159.

# DISCLOSURES

ENB, JLP, and RW are employees of Mallinckrodt Pharmaceuticals. RBD is an employee of Harris Poll.