

### THE MS DECISIONS STUDY

# What Factors Influence Changes in MS Management? Comparing the Perspectives of Patients and Health Care Providers using Nominal Group Technique

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Results

### Background

- Little is known about differences between patient or health care provider concerns that may prompt a change in the management of Multiple Sclerosis (MS).
- Incorporating patient perspectives into treatment decisions promotes shared decision-making and values-based choices.

### **Study Objectives**

To compare factors that may influence changes in the management of MS between patients with MS and health care providers.

### **Inclusion Criteria**

#### **Patients:**

- Confirmed MS diagnosis
- Age 21-75
- Web access
- Targeting racial diversity
- **HCPs:**
- Neurologist, PA, RN or NP;
- MS focus,
- Sees  $\geq$  10 MS patients/month
- National sample
- National sample

### Methods

### Nominal Group Technique (NGT):

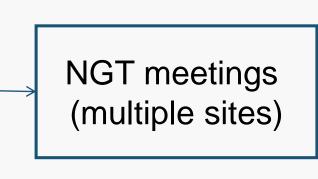
- Structured focus group
- Elicits and prioritizes responses to a single question
- NGT Steps:
  - 1. Participants silently write down ideas to the question
- 2. Round-robin recording of ideas then group discussion
- 3. Private vote on item importance with weighted ballots
- Resulting prioritized lists of items were combined

### **NGT Questions**

- Patients were asked: "What factors would make you decide to change how you manage your MS?"
- HCPs were asked: "What factors would make you decide to change how you manage your patient's MS?"

### **Overall Study Design**

NGT Question Development (cognitive interviews)



**HCP NGT** 2 NGT groups 2 sites 15 participants

MS Patient NGT 2 NGT groups 2 sites **15 participants** 

\*Biogen reviewed the content and provided feedback. Authors had full editorial control of the poster and provided their final approval of all content.

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## **Raw NGT Findings: Top 10 Factors**

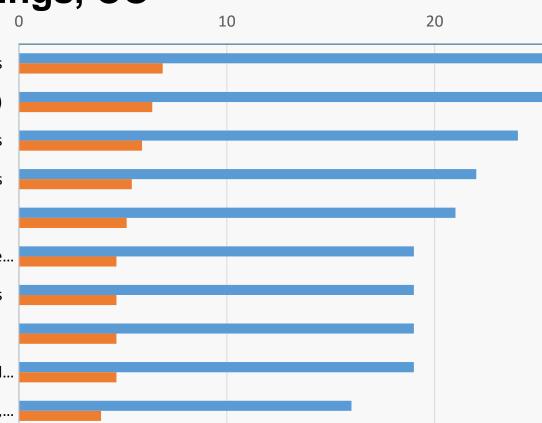
#### Patients: Atlanta, GA

#### f I was getting worse gradually/progression / losing physical and mental function

- When MS is not stable (new symptoms, or not being able to manage existing...
  - A new or better treatment is available
  - If my physical activity becomes limited
  - Changes in insurance coverage
- If other people with similar MS had good results with a new DMT treatment
- If I keep having relapses The inconvenience/difficulty/cost of changing treatment (any treatment)
- Change in my career or job
- If I learn about non-DMT treatments that can help manage symptoms (e.g....
- An outside observer suggests that something has changed.

Sum Weighted Importance (%

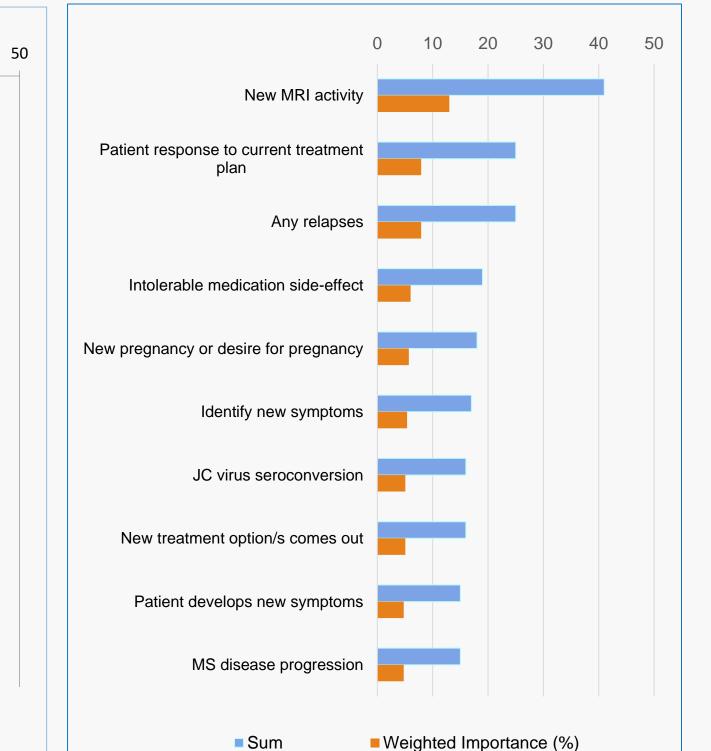
#### Patients: Colorado Springs, CO



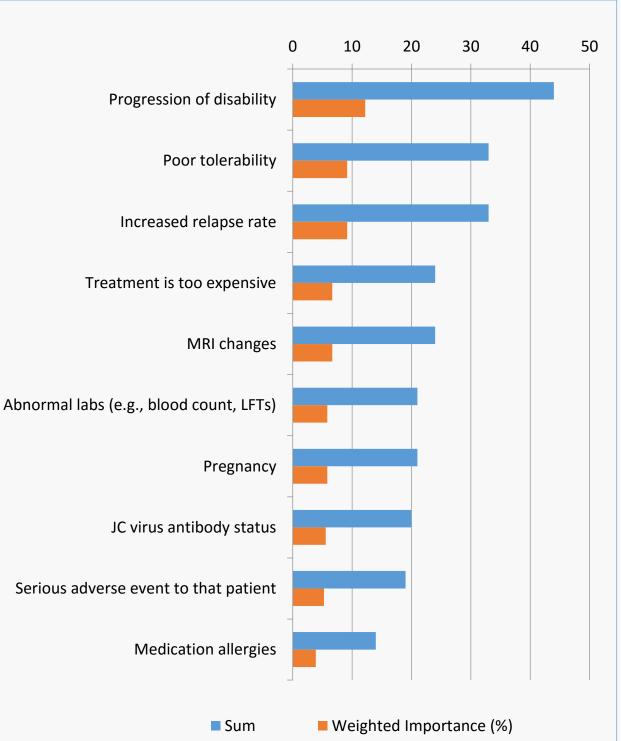
Changes in the severity of my symptoms

- ortance of holistic approaches (e.g. diet exercise meditation)
  - Financial challenges limit treatment /management options
- nowledge of resources available (including transportation, financial,
- The ability to pay for medication/financial challenges in obtaining the..
  - More information about new treatment options
    - If I'm starting to decline
- Provider really demonstrating changes (or not) over time, comparing meaningful
- More active support and better communication/discussion with your provider,.

### HCPs: Denver, CO



### HCPs: Colorado Springs, CO



### **Comparison of Factors Influencing Treatment** Changes, Patients versus HCPs, by Category

(Shading indicates items that were unique to either patients or HCPs)

#### **Patient Factors**

**HCP Factors** 

lew or better treatments are available	
others with similar MS had good results with a new DMT	New treatment option/s comes out
inding out about new or better treatment	New research findings
wareness of non-DMT treatments or holistic approaches	
·	
ifestyle/convenience	
amily issues	Detient's desire for change
convenience of changing treatment	Patient's desire for change
ccess to exercise equipment	
Disease progression or relapses	
tarting to decline /getting gradually worse	Progression of disability
osing physical or mental function	Any relapses/Increased relapse rate
hysical activity becomes limited	
aving relapses or more relapses	MS disease progression
hange in MRI	MRI changes/New MRI activity
rovider demonstrates objective evidence of change (or not)	
IS is not stable (new symptoms, unable to manage symptoms)	Identify new symptoms/ Worsening of chronic
	symptoms (e.g. fatigue)
inancial concerns	
hange in financial situation	Insurance and financial availability
hange in insurance coverage	Change in insurance provider
hange in my career or job	
reatment is too expensive	Treatment is too expensive
Inable to handle treatment	
etting tired of dealing with MS	Patient response to current treatment
omplications or adverse effects arise from the med	-Serious adverse event to that patient
•	-Abnormal labs/Intolerable side-effect
	-Medication allergies
ymptoms of depression / helplessness develop/worsen	
	Pregnancy /desire to become pregnant
aring and well-informed medical team	
ore active support and better communication with provider	
aving a supporting neurologist who is well informed	
change in provider	
ledical Background	
ly age	
iagnosis of PML	JC virus seroconversion
Support	
nowledge of resources available (transportation, \$)	
nd of a clinical trial that provides support and treatment	
Other	
	Poor tolerability
	Lack of compliance
	New safety concerns of a DMT

### **Key Findings**

- The most important factor for patients was changes in severity of symptoms/disease progression.
- The most important factors for providers were new MRI activity and progression of disability.
- Both patients and HCPs prioritized slowing disability.
- Only patients prioritized awareness of holistic approaches, availability of resources, and inconvenience.
- Only providers prioritized concerns about safety, adverse events, and non-adherence.

### Implications

- There were differences in the factors that might influence treatment changes between patients and HCPs.
- There were differences in how similar factors were articulated by both groups.
- Assessing factors that influence patient decisions about changing treatment should improve patientprovider communication and treatment management.
- Communication tools are needed to bridge communication gaps and support shared decision making in discussions about MS treatment.

### Limitations

- Recall bias
- Small sample size limits generalizability
- Cross-sectional study design

### Next Steps

Develop and validate preference assessment instrument

### References

- 1.Delbeq AI, van de Ven AH, Gustafson DH. (1975): Group Techniques for Program Planning: A Guide to Nominal and Delphi Processes. Glenview, III: Scott, Foresman Co. 2.Risk Communication Advisory Committee and consultants (2013) Communicating
- Risks and Benefits: An Evidence-Based User's Guide. Eds: Fischhoff B, Brewer NY, Downs JS. U.S. Department of Health and Human Services; FDA.
- 3. Stacey D, Légaré F, Col NF, et al. Decision aids for people facing health treatment or screening decisions (Review). The Cochrane Collaboration, Cochrane Lib 2013,(11).