

STATE OF
MIS

REPORT, Volume 2:
Spotlight on Expectations,
Decision-Making and
Treatment Satisfaction

INTRODUCTION

With the advent of additional therapies in recent years, people living with multiple sclerosis (MS) have more treatment options than ever before.

Being able to choose among treatment options is a significant breakthrough, but also raises important questions: How do patients know which treatment is right for them? How do neurologists guide their patients in treatment selection? And how satisfied are patients with their chosen treatment?

The best way to find out is to ask. So we did.

As the centerpiece of a comprehensive State of MS initiative, an international survey polled people living with MS and healthcare providers who treat the disease about key aspects of MS care today. Commissioned by Biogen and conducted online by Harris Poll, the survey focused on patient-physician communication and treatment expectations, goals, and challenges for people living with MS and their physicians.

The first Report on the State of MS focused on patient-doctor communication: which topics are comfortable, which ones are challenging, and how to improve all aspects of communication. But there is still more to be said about how and how well patients and their healthcare providers speak to one another. That's why this new Report includes even more information about doctor-patient communication, specifically as it relates to choosing and using a disease-modifying therapy (DMT).

When selecting one treatment over another, how is that responsibility shared between the neurologist and the patient? When and how are treatment goals set? Does the patient's experience with that DMT regimen turn out to be what he or she expected? How is treatment success defined and measured? These are vital decisions that are unique to each patient's situation, but the need for good communication is common to all.

As the survey shows, many people with MS report being involved in their treatment. More than half of patients report being very satisfied or satisfied with their DMT and 82 percent participated in the decision-making process when choosing their DMT. More satisfied patients tended to report being very comfortable speaking about their MS to their neurologist and were more likely to report that they took a more active role in choosing their DMT compared to less satisfied patients.

Just as our first Report aimed to be a catalyst for improving doctor-patient dialogue about MS and living with the disease, we hope this new Report will encourage more open communication about treatment choices, goals and challenges. We encourage shared decision-making and shared treatment priorities as the most effective way to achieve the best possible results for each person living with MS.

– **The State of MS Consortium**, an international steering committee of treating neurologists and representatives from patient advocacy groups from five countries

ABOUT MS

Multiple sclerosis—one of the most common causes of neurological disability—is a chronic, often disabling disease that affects the central nervous system, which is made up of the brain, spinal cord, and optic nerves. MS rarely affects two patients in exactly the same way and symptoms may range from mild to moderate or severe. The patients who participated in the State of MS survey reported experiencing the full range of common MS symptoms.

State of MS Patient Symptoms



Q: Which of the following symptoms of multiple sclerosis, if any, have you experienced? Please select all that apply.
n=982 patients

STATE OF MS SURVEY PATIENT SNAPSHOT

AVERAGE AGE

45



TWO-THIRDS
WOMEN (63%)



ONE-THIRD
MEN (37%)

MS TYPE

46%

Nearly half
with Relapsing-
Remitting MS

2%

Other

29%

Secondary-
Progressive MS

5%

Not Sure

11%

Primary-
Progressive MS

6%

Progressive-
Relapsing MS

BASE
n=982



3 in 5 patients (62 percent)
reported having taken a
DMT to help treat MS

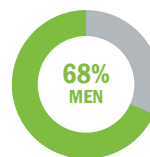


Of these patients, nearly
3 in 4 (74 percent) were
currently taking a DMT

PATIENT RESPONDENTS BY COUNTRY (Total 982)



STATE OF MS SURVEY NEUROLOGIST SNAPSHOT



TOTAL OF 900 NEUROLOGISTS
WHO TREAT MS PATIENTS:

- GERMANY (n=200)
- ITALY (n=200)
- SPAIN (n=150)
- UK (n=150)
- U.S. (n=200)




GOOD COMMUNICATION, IMPROVED CARE: A CONTINUOUS CYCLE

Open and honest communication is a vital component of providing high-quality care to people living with MS.

In the first State of MS Report, we examined overall satisfaction with patient-physician communication. We also focused on survey data that show how patients and neurologists communicate about MS symptoms and what factors help and hinder effective dialogue in the doctor’s office.

Let’s revisit the survey data to take a closer look at patient treatment satisfaction, challenges and adherence. The data imply that achieving patient treatment satisfaction may require frank communication with a physician at each stage of the treatment cycle, from selecting a treatment to adhering to the prescribed treatment.

IN THIS REPORT, WE EXAMINE THREE MAIN FACTORS THAT MAY AFFECT THE TREATMENT SATISFACTION OF PEOPLE LIVING WITH MS:

-  Treatment expectations
-  Patient input into treatment decision-making
-  Treatment challenges and adherence to therapy

Most surveyed MS patients (62 percent) had taken a DMT at some point in their lives and, of those, a majority (74 percent) were currently taking one.

THE SURVEY RESULTS SHOWED THAT PATIENTS’ SATISFACTION WITH THEIR CURRENT DMT IS SPLIT:



More than half of patients currently taking a DMT (58 percent) report feeling either very satisfied or satisfied.



42 percent report feeling only somewhat satisfied or not at all satisfied.

Additionally, we learned that patients who are satisfied with their DMT are more likely to say their treatment closely meets expectations than those who are not satisfied (67 percent versus 44 percent). The satisfied patients are also more likely to say that their healthcare provider is honest in setting expectations for therapy success (93 percent versus 85 percent).

HOW IMPORTANT ARE PATIENT EXPECTATIONS?

“Setting realistic expectations of the disease-modifying treatment is critical to success. Not only is it important to establish those expectations when beginning therapy, it is important to check in on them as treatment progresses. The disease-modifying treatments are an important part of overall MS management, and are known to limit new MS disease activity – including relapses, new MRI activity, and, to some extent, disease progression. An open and honest dialogue is essential for patients and healthcare providers to develop a mutual understanding of treatment expectations.”

*Kathy Costello, R.N., N.P., Vice President,
U.S. National Multiple Sclerosis Society (NMSS)*

TREATMENT GOALS PAVE WAY FOR REALISTIC EXPECTATIONS

What is involved in setting patients' treatment expectations?
Clear patient-physician communication, of course.

**ON AVERAGE, NEUROLOGISTS DISCUSS TREATMENT GOALS WITH
ABOUT FOUR IN FIVE PATIENTS (78 PERCENT) PRIOR TO STARTING A DMT.**

A communication gap of sorts exists: More than one in five patients who have taken a DMT say their neurologist either did not set any treatment expectations (12 percent) or could not recall if they were set (10 percent). A patient's lack of awareness of a treatment goal may imply a lack of engagement in his or her own medical care or a lack of understanding of the chosen DMT and what to expect.

"Every neurologist should discuss treatment goals when they decide to put a patient on a DMT. While nearly 80 percent of physicians discussing treatment goals with their patients is quite good, this number should be even higher."

Robert Weissert, M.D., Ph.D., Germany

"It's almost impossible not to establish treatment goals with patients, because they often ask if the treatment will cure their MS. That gives the neurologist the opportunity to clarify and set the actual goals, which could include reduction in relapses, future new attacks and new lesions on MRI. I think the data reflect the fact that treatment goals are a learning process for the patient: they are not necessarily clearly established from the very beginning, but rather something the patient learns through his or her MS journey."

Mar Tintore, M.D., Ph.D., Spain

"There may be some different interpretations of what neurologists and patients mean by 'treatment goals.' I hope physicians would discuss treatment goals with virtually every patient, especially when we already know that more joint goal-setting can increase patient satisfaction."

Maggie Alexander, Chief Executive,
European Multiple Sclerosis Platform (EMSP)

PATIENT INPUT CONNECTED TO SATISFACTION

Both patients and neurologists indicate that patient input into the DMT decision-making process influences satisfaction.

MORE THAN 9 IN 10 NEUROLOGISTS (92 percent) recognize that patients are **more likely to be satisfied with their DMT experience if they provide input** when choosing their treatment plan.

AND NEARLY ALL NEUROLOGISTS (97 percent) agree that it is **important for MS patients to provide input** into choosing their treatment plan.

FROM THE PATIENT PERSPECTIVE, A STRONG MAJORITY (69 percent) of satisfied patients characterize themselves as an **equal partner or the primary or sole decision maker** in choosing their DMT (versus 58 percent of those who are less satisfied).

MOREOVER, Patients who are equally or more involved treatment decision makers are more likely to say they are very satisfied with their DMT as opposed to patients whose healthcare provider is the sole or primary decision maker (29 percent versus 14 percent).

There is also a positive link between satisfaction with a DMT and patients' comfort with speaking about their MS to their neurologist: 64 percent of patients satisfied with their DMT say they are very comfortable speaking with their neurologist versus 43 percent of patients who are less satisfied with their DMT. The opposite is true, too: one in four patients who are less satisfied with their DMT say they are uncomfortable talking to their neurologist, compared to only nine percent who are satisfied with their DMT.

"I consider it extremely important, both in general and in my own practice, that patients be given both the information and the opportunity to participate in decisions about their own treatment. I spend a lot of time with patients, especially in the early stages following diagnosis, to make sure that they understand all of their treatment options. It is difficult but important to understand that the best chance of preserving function in future decades often comes from pursuing aggressive treatment now, which means making the patient the optimal partner in the process."

Antonio Uccelli, M.D., Italy

"The important message from these data is that we have room to improve. These results speak to the need for collaborative relationships with healthcare providers. People with MS want to be more involved with decision-making so they need better tools and resources to enable them to have better conversations with their healthcare providers."

Kathy Costello, R.N., N.P., Vice President, U.S. NMSS

"People who have been closely involved in shared decision-making are the most satisfied. Those who have not had such discussions are less satisfied possibly because of the greater risk of having unrealistic expectations. This confirms that shared decision-making is the way to go, but this can mean different things to different people and the process should therefore be tailored according to individuals' needs."

Maggie Alexander, Chief Executive, EMSP

"We have seen a correlation between treatment satisfaction and joint decision-making. Patients in Spain tend to be less involved in the decision-making process, so this needs to be improved."

Mar Tintore, M.D., Ph.D., Spain

SHARED PRIORITIES WHEN CHOOSING A DMT

It is helpful to know that both patients and neurologists consider both safety and side effects as top factors for patients to know when making decisions about DMTs.

While many patients agree that it's important to know about a treatment's safety (**51 percent**) and its potential side effects (**51 percent**), they have a diverse set of informational needs when choosing a DMT.

ADDITIONAL FACTORS CITED BY PATIENTS INCLUDE



Physicians recognize that individual patients have different considerations when making treatment decisions, with 98 percent noting that treatment plans should always be customized to their MS patients.

“It is very important to listen to the patient at all times. If there are side effects, the neurologist must adapt the DMT to suit the patient’s needs and priorities. The neurologist only sees the patient for a short time, but the patient must live with the disease, the DMT and its side effects constantly, and we as physicians must remember that when we prescribe and assess DMTs.”

Robert Weissert, M.D., Ph.D., Germany

“It’s not enough to just listen to the patient: the healthcare provider must really understand the patient’s needs and concerns. It can often be difficult to separate the effects of the actual disease from DMT side effects. Furthermore, the terminology used by patients and healthcare providers can differ, which adds to the potential for miscommunication. These factors can make it easy for busy healthcare providers to overlook the impact of symptoms on the daily life of their patients.”

David Jones, M.D., United States

“Doctors are trained to look at drugs from a clinical and scientific perspective. Patients naturally start with a more holistic view. Clearly we care about patients’ experiences on a therapy, and that’s part of choosing a drug, but it’s not the entire focus of DMT selection, which must bring in long-term effects and potential benefits. Physicians must play their role in the process, bringing their knowledge of the clinical science and the potential long term impact of a therapy to balance against perceived negative impact on daily life. But there is a delicate balance to be found and neurologists and patients should feel comfortable discussing openly what they see as important.”

Martin Duddy, M.D., United Kingdom

TREATMENT CHALLENGES AND ADHERENCE: CAN WE TALK ABOUT IT?

Because MS is a chronic disease, concordance with treatment is a long-term commitment.

Patients and neurologists agree on the top two challenges that patients face in managing their MS treatment: side effects or tolerability of the treatment and uncertainty if the treatment is working. **Nearly half of neurologists (49 percent) also believe that patients' lack of acceptance of the disease is a top challenge.** Far fewer patients (17 percent) mention this issue, which may create the potential for misunderstanding.

49% | **NEARLY HALF OF PATIENTS WHO HAVE BEEN ON A DMT REPORT NEVER SKIPPING DOSES OF THEIR DMT.**

32% | **OF THOSE WHO DO SKIP DOSES, NEARLY ONE-THIRD REPORT NOT TELLING THEIR HEALTHCARE PROVIDER WHEN THEY SKIP A DOSE.**

Patients say the main reasons for skipped doses are: **they forgot (43 percent); the side effects (22 percent); and they were feeling better (15 percent).** However, neurologists believe that their patients experiencing side effects (73 percent) represents the greatest cause of skipping treatments.

What can we learn from these inconsistencies in responses from neurologists and people living with MS?

“As a group, we physicians need to be better at listening because, all too often, we hear what we expect to hear. The fact is that, once you’re on a chronic oral therapy, for example, life can get in the way and you can easily forget a daily pill every so often. But with some of the MS DMTs, you get an injection or an infusion once a week or once a month at your neurologist’s office. The more important question is: What do you do when you realize you’ve missed a dose? And, as your healthcare providers, we need to ask what would have helped you to remember this time and how can we help you to remember in the future?”

Gilmore O’Neill, Vice President, Multiple Sclerosis Research and Development, Biogen

“Having an open dialogue between patients and healthcare providers is so important because patients are more likely to be adherent in that kind of atmosphere. If you as a patient are not satisfied with your therapy, you’re not likely to take it. As physicians, we have to address our patients’ issues to create a sense of satisfaction before we start treating them. In fact, when it’s time to discuss treatment choices, that’s a special appointment in my practice. The patient brings family members, and everyone feels invested.”

Sibyl Wray, M.D., United States

“If we believe the way to improve patient adherence is purely through minimizing side effects, which is what the neurologists’ responses seem to suggest, that ignores the underlying human factors revealed in the patient answers. The only way to improve adherence is to recognize the true reasons people aren’t taking their treatments and then address those reasons. If we are aiming at the wrong target, we will not achieve anything. It seems we should be focusing more on maximizing patients’ memories, perhaps with reminder calls, reminder texts or mobile phone alerts.”

Martin Duddy, M.D., United Kingdom

THE GLOBAL STATE OF MS SURVEY: NUTS AND BOLTS

The State of MS initiative has one overarching goal: to better understand the MS experience worldwide, including all aspects of communication between patients and physicians.

To accomplish that goal, Biogen collaborated with the STATE OF MS CONSORTIUM, an international steering committee of treating neurologists and patient advocacy representatives from five countries:



THE SURVEY INVOLVED A TOTAL OF
982 ADULTS WITH MS

**900 NEUROLOGISTS
WHO TREAT MS PATIENTS**
IN ONE OF FIVE COUNTRIES



Harris Poll conducted the survey online in 2014, asked parallel questions of both patients and neurologists and applied a post-weight to the total results giving each country equal weight.

CONCLUSION

All in all, the State of MS initiative reveals much that is positive about the important relationship between neurologists and people who live with MS. A majority of MS patients participate in making decisions about their DMT and more satisfied patients tend to be more comfortable speaking about their MS to their neurologist compared to less satisfied patients. We believe treatment satisfaction is related to the degree of patient input into the DMT decision-making process. The State of MS survey results suggest that treatment satisfaction could potentially be improved by better understanding mutual expectations: What are my patient's top treatment priorities? Why does my doctor want me to take this treatment? The way to increase satisfaction may be to communicate more directly and openly. For patients, that means telling your neurologist your

hopes and fears relating to MS and DMTs. For neurologists, that means listening to each patient as an individual and asking targeted questions when necessary to understand his or her true treatment priorities and challenges. As State of MS Consortium members, we strongly believe that this study can help physicians and people with MS around the world. We have presented these findings to our colleagues at national and international neurology conferences. However, we remain profoundly aware that the most important doctor-patient communication takes place in the exam room, one conversation at a time. We hope you make your next one candid and heartfelt.

– The State of MS Consortium

THE STATE OF MS CONSORTIUM

When leading experts in the care of MS and top advocates for people living with MS collaborate, exciting things happen.

The members of the State of MS Consortium, who helped develop the survey, are passionate about improving MS care because they work with patients across the U.S. and Europe every day.



MAGGIE ALEXANDER

Maggie Alexander is Chief Executive of the European Multiple Sclerosis Platform (EMSP), which represents national MS organizations from 34 member states throughout Europe. She also sits on the boards of the European Federation of Neurological Associations and the European Brain Council.



KATHY COSTELLO

Kathy Costello is the vice president of Healthcare Access at the U.S. National Multiple Sclerosis Society (NMSS) and a nurse practitioner.



MARTIN DUDDY

Martin Duddy, M.D., is a consultant neurologist and department head at the Royal Victoria Infirmary in Newcastle-Upon-Tyne (UK) and an associate editor of *The Multiple Sclerosis Journal*.



DAVID E. JONES

David E. Jones, M.D., is an assistant professor in the University of Virginia Health System (U.S.) and associate director of clinical operations at the James Q. Miller Multiple Sclerosis Clinic.



NANCY LAW

Nancy Law is a consultant with Nancy Law Consulting, LLC, and former executive vice president of the U.S. NMSS.



MAR TINTORE

Mar Tintore, M.D., Ph.D., is a senior consultant neurologist at the Multiple Sclerosis Centre of Catalonia, Hospital Vall d'Hebron (Barcelona, Spain) and an editor of the *Multiple Sclerosis Journal – Experimental, Translational and Clinical*.



ANTONIO UCCELLI

Antonio Uccelli, M.D., is a faculty member in the Department of Neurosciences, Ophthalmology and Genetics at the University of Genoa (Italy).



ROBERT WEISSERT

Robert Weissert, M.D., Ph.D., is a senior physician and researcher at the University of Regensburg (Germany).



SIBYL WRAY

Sibyl Wray, M.D., is the director of Hope Neurology Multiple Sclerosis Center in Knoxville, Tennessee, (U.S.) and an active clinical researcher.