

STATE OF MS



REPORT:
Improving Physician-Patient
Dialogue About Multiple Sclerosis
Around the World

INTRODUCTION

When it comes to information about living with multiple sclerosis (MS), **more is better.** More than nine in 10 patients say – and neurologists tend to agree – that they like to know everything about their MS, whether it’s good or bad.

How do we know? We asked.

As part of a comprehensive State of MS initiative, an international survey sought to understand MS care by surveying those in the trenches: people living with and treating the disease.

Commissioned by Biogen Idec and conducted online by Harris Poll, the survey focused on a key aspect of MS care: communication between patients and their doctors.

When communication is done well, it reinforces a healthy partnership between clinicians, patients and others actively involved in MS care.

And for truly successful treatment regimens to be developed and maintained, patient participation is fundamental.

Our commitment to improving the lives of MS patients – an effort that extends well beyond medication – prompted this timely analysis.

What did we learn? In short, despite the generally positive assessment of current practice in MS, certain aspects of communication between doctors and patients could be better. It’s our fervent hope that the survey will serve as a catalyst for improvement – not only in doctor-patient dialogue, but also in information more precisely targeted to the answers patients and neurologists still seek about MS.

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

“The implications of a communication gap between physicians and patients are huge, impacting happiness, fulfillment and quality of life. It’s very hard to help patients deal with the things that matter to them if we’re not talking about those things or aren’t aware of them. This survey shows how important it is to build a trusting relationship between physicians and patients in order to optimize each patient’s life with their disease. Using this insight, we can educate both sides about creating an environment that allows the honest exchange of what concerns them about MS in day-to-day life. We can also unite physicians and drug developers to focus ongoing efforts on therapeutic improvements in aspects that most concern patients. Lastly, we can ensure we achieve the best possible outcomes for patients so they feel the disease minimally impacts their lives.”



Mar Tintore, M.D., Ph.D.
MS Centre of Catalonia, Spain

“It’s very important – and very difficult – to gather the opinions of many MS patients and hear their answers to a wide range of questions about their experiences. This survey achieves that. Patients can always provide their doctors with a checklist of symptoms to discuss during office visits, but this step alone isn’t likely to improve communication between them. This new data can prompt crucial discussion about how physicians and patients speak together about symptoms – especially hidden ones – which can help neurologists know if they’re helping change patients’ lives for the better.”



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

ABOUT MS

Multiple sclerosis rarely affects two patients in exactly the same way.

A chronic, often disabling disease that attacks the central nervous system – made up of the brain, spinal cord, and optic nerves – MS is estimated to affect about **2.3 million people worldwide**¹, with approximately 700,000 people living with the disease in the European Union² and 400,000 in the United States.³

MS symptoms may be mild or severe, ranging from fatigue or numbness in the limbs to paralysis, memory problems or loss of vision. While some people with MS experience little disability in their lifetime, as many as 60 percent may be unable to walk without assistance 20 years after onset. One of the world's most common neurological disorders, MS is the leading cause of non-traumatic disability in young adults in many countries.⁴

ABOUT THE STATE OF MS SURVEY

The State of MS survey was created with one overarching goal: to better understand the MS experience worldwide, especially communication between patients and physicians.

To accomplish that goal, Biogen Idec collaborated with the State of MS Consortium, an international steering committee of treating neurologists and patient advocacy organization representatives across five countries: Germany, Italy, Spain, the United Kingdom (UK), and the United States (U.S.).

..... MS is one of the world's
most common neurological disorders

APPROXIMATELY
400,000
people are living
with MS in the
United States



APPROXIMATELY
700,000
people are living
with MS in the
European Union

..... MS is estimated to affect
about **2.3 MILLION people worldwide**

Conducted in March/April 2014, the State of MS survey is a global assessment of the needs, experiences and attitudes of people living with MS and neurologists who treat MS. The findings will drive dialogue around key issues facing the MS community, including communication shortcomings that may affect MS care – and ultimately, affect outcomes.

This survey offered a broad global reach, surveying a total of 982 adults with MS and 900 neurologists who treat MS patients from Germany, Italy, Spain, the UK and the U.S.

REFERENCES

- 1 Multiple Sclerosis International Federation, Atlas of MS 2013. Epidemiology of MS.
- 2 EMSP. EMSP Members. Date Accessed: December 3, 2014. <http://www.emsp.org/emsp-members>
- 3 NMSS. MS Prevalence. Date Accessed: December 3, 2014. <http://www.nationalmssociety.org/about-the-society/ms-prevalence/index.aspx>
- 4 Multiple Sclerosis International Federation, Atlas of MS 2013.

WHO WERE THE PATIENTS

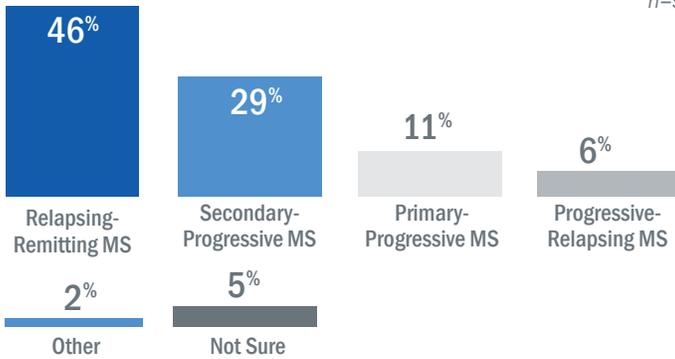
AVERAGE AGE

45



MS TYPE

BASE
n=982



DIAGNOSIS



Patients ranged from newly diagnosed to those living with MS for more than 3 decades

BY COUNTRY

(Total 982)

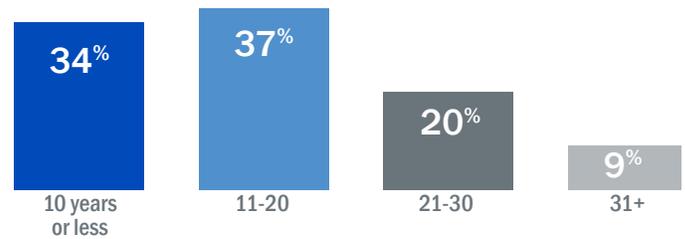


WHO WERE THE NEUROLOGISTS



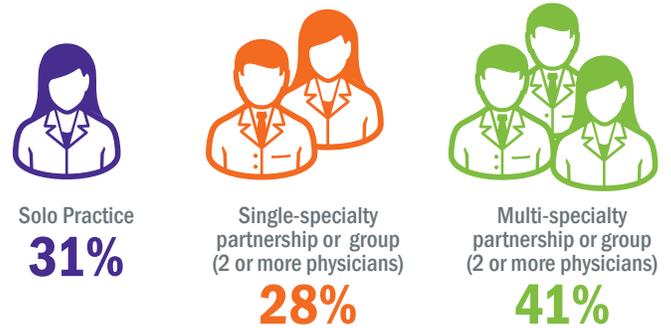
YEARS IN PRACTICE

BASE
n=900



OFFICE

BASE
n=900



BY COUNTRY

(Total 900)



Survey Methodology

Harris Poll, on behalf of Biogen Idec, surveyed 982 adults diagnosed with multiple sclerosis (“MS patients”) and 900 neurologists who treat MS patients (“neurologists”) within Germany, Italy, Spain, the UK and the U.S. between March 18 and April 25, 2014. Within the U.S., MS patient responses were weighted for gender, age, region, race/ethnicity, education and income where necessary to align with

actual proportions in the U.S. MS patient population; U.S. neurologist results were weighted for gender, region, and years in practice where necessary to align with actual proportions in the U.S. neurologist population. A global post-weight analysis was applied to the total data in order to give each country equal weight.

ABOUT THE STATE OF MS CONSORTIUM

Nobody is more concerned about MS than those living with or treating the disease. To that end, each member of the State of MS Consortium, who helped develop the survey, has a stake in improving MS care because they work with patients across the world every day.



MAGGIE ALEXANDER

Maggie Alexander is chief executive of the European Multiple Sclerosis Platform (EMSP), which represents 39 member organizations

across 34 member states throughout Europe. With 25 years of management experience in the health and medical charity field, Maggie also sits on the European Federation of Neurological Associations Board.

“When people are facing serious long-term conditions, they often endure a loss of autonomy and dignity. One of the ways they can recover that is having timely information that enables them to make informed choices that contribute to their well-being.”



MARTIN DUDDY, M.D.

Martin Duddy, M.D., is a consultant neurologist with a special interest in MS at the Royal Victoria Infirmary in Newcastle-upon-Tyne, where he

is head of the department. Involved in numerous clinical studies, he is also an associate editor of the *Multiple Sclerosis Journal*.

“This survey was a highly interesting initiative, exploring the very different healthcare models for MS in different countries. I was particularly interested in seeing how the UK model fared, as we have many MS nurses and fewer neurologists.”



NANCY LAW

Nancy Law is the executive vice president of programs and services for the U.S. National Multiple Sclerosis Society (NMSS). Leading the

Society’s efforts to achieve high-quality programs nationwide for people with MS and their families, Nancy has also authored many articles and manuals.

“This survey gets at some really significant and valid answers. One of our goals – to help people affected by MS to live their best lives – has got to include making sure patients know how to communicate with their physicians and facilitating the dialogue needed to ensure the best care.”



DAVID E. JONES, M.D.

David E. Jones, M.D., is an assistant professor in the University of Virginia Health System working in the Department of Neurology.

He is associate director of clinical operations at the James Q. Miller Multiple Sclerosis Clinic, and has also served on numerous professional committees.

“Years ago, medicine was more paternalistic, but the pendulum has swung and now there’s more of an equal footing between doctors and patients. It’s important for physicians to make sure we’re meeting our patients’ needs and not just what we think are their needs.”



MAR TINTORE, M.D., PH.D.

Mar Tintore, M.D., Ph.D., is a senior consultant neurologist at the Multiple Sclerosis Centre of Catalonia, Hospital Vall d’Hebron in Barcelona, Spain,

which treats more than 4,000 MS patients. Her research focuses on such aspects as prognostic factors and MS treatment. She is also an editor of the *Multiple Sclerosis Journal – Experimental, Translational and Clinical*.

“This survey enables us to understand the feelings of MS patients from many different countries. Here in Spain, the current economic struggles may impact their overall perception. The social support these patients are receiving is still very important.”



ROBERT WEISSERT, M.D., PH.D.

Robert Weissert, M.D., Ph.D., is a senior physician in neurology and a researcher at the University of Regensburg in Germany. He has made

important contributions to the understanding of neuroimmunological diseases, with a special focus on MS.

“For years there’s been very good care for MS patients, so it’s interesting to see certain areas that may not be perceived the same way by patients and neurologists – especially in different countries. The survey can help make people aware of these discrepancies and determine where we as a society can perhaps change things to help patients more.”



ANTONIO UCCELLI, M.D.

Antonio Uccelli, M.D., is a faculty member in the Department of Neurosciences,

Ophthalmology and Genetics of the University of Genoa in Italy. His research activities have focused on MS and adult stem cells and earned him numerous accolades in the field.

“Not only are there communication gaps still present between healthcare professionals and individuals with MS, but in many situations there might be a different perception of what issues are relevant to MS care. In Italy, along with many other countries, most neurologists can’t dedicate their practices solely to MS, and the difficulty finding time to talk to patients can hinder discussion.”



SIBYL WRAY, M.D.

Sibyl Wray, M.D., is director of Hope Neurology Multiple Sclerosis Center in Knoxville, Tenn. Acting as lead researcher in more than

40 clinical trials in MS, she has also published and presented broadly about her research.

“I just think it’s important to help physicians and patients communicate better. If we don’t know the right questions to ask patients when they’re not asking them, along with how they’re getting their information and how we can best help them educate themselves, then we’re not doing our jobs.”

IMPACT OF MS ON LIFE

MS patients are largely an optimistic group, but few see their general health as good. Patients 45 and older are more likely than younger patients to describe their health as poor – a difference that might be linked to the length of time they’ve been affected by the disease.

Overall, however, most patients (62 percent) believe their condition has negatively impacted their life “a great deal” or “a lot.”

Despite this assessment, **a strong majority of MS patients (69 percent) still feel optimistic about their future**, and 60 percent of neurologists agree.

“It’s difficult to think of parts of patients’ lives that aren’t affected by MS. Obviously, it varies from patient to patient, but I think there’s an overall impact on a person’s ability to feel in control of his or her life. Also, hidden issues with mood, cognition and fatigue – which are symptoms not always addressed as effectively as walking or vision problems – can be as challenging as the more obvious ones. In many cases, a person who needs a wheelchair but is cognitively intact is more able to be employed. And we know that those issues impact relationships as well.”



Nancy Law
U.S. National Multiple Sclerosis Society

“When I think back on my conversations with individuals with MS, it’s not always the obvious physical disability caused by the disease that strikes them. I’d say one of the cardinal features is the uncertainty of their condition, its progression and the continuing losses. They gear up to deal with one loss – a function or an ability to participate – and adapt to that, only to find themselves having to deal with another loss six months later. That’s extremely hard to take.”



Maggie Alexander
European Multiple Sclerosis Platform

WHAT DAY-TO-DAY ASPECTS OF LIFE DO PATIENTS FEEL THEIR MS NEGATIVELY IMPACTS MOST?

Ability to participate in **hobbies and social activities**



74%



71%

Job/career or ability to work

Overall **mood**



65%



63%

Ability to **travel long distances**



62%

or even for every day needs

61%

Ability to perform **activities of daily life**



51%

Sex life

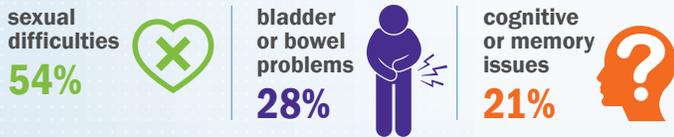
UNDERSTANDING COMMUNICATION BETWEEN PATIENTS AND PHYSICIANS

Here’s the good news: MS patients and physicians are generally satisfied with their conversations related to the disease. More than eight in 10 patients feel comfortable talking about their MS with their neurologists, characterizing their relationship as honest, comprehensive and helpful. And nearly all neurologists feel they have an open dialogue in which their patients can ask any question they wish.

But there is a bit of bad news. In this case, just mentioning certain MS symptoms prompts hesitation among both patients and neurologists. Nearly one in five patients report discomfort speaking about even typical MS symptoms such as:



Patients also say they’re uncomfortable discussing some of the disease’s more sensitive and private symptoms, such as:



But neurologists tend to overestimate their patients’ unease with these topics – in fact, patients aren’t as reluctant to talk about these topics as doctors anticipated.

What might prevent patients and neurologists from proactively discussing certain symptoms? And how can a communication gap affect MS care and its outcomes?

“Often, a gender and age difference between neurologists and patients can prevent proactive discussion of MS symptoms. In the survey, roughly two-thirds of patients were women and two-thirds of doctors were men, and patients tended to be younger than doctors. We need to address this disparity because intimacy issues can make a huge difference in quality of life – not just sexuality but also bowel and bladder issues. If they’re encouraged, I think patients will be more comfortable talking about it.”



Sibyl Wray, M.D.
United States

“Not talking about sensitive issues may lead to underestimating these problems and an inability to treat them, which is particularly bad because they’re aspects of MS that can potentially be addressed. For example, we’ve made a lot of advances in managing sexual problems or bowel or bladder problems. Cognitive issues can also be addressed.”



Antonio Uccelli, M.D.
Italy

“I’m now asking my patients more about some of their more sensitive symptoms, such as bladder dysfunction. In men, this is normally also associated with sexual dysfunction, so I go into more detail with them about these things. Based on the survey, I now understand that patients are afraid of asking – so I give them a bit more information or make it easier for them to ask me.”



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

WHAT HINDERS EFFECTIVE DIALOGUE?

Most neurologists want to provide the best MS care available. But that can only happen through optimal communication between physicians and patients – a proactive partnership in which no assumptions are made about what patients need or want.

What are the biggest barriers to this ideal? Perhaps unsurprisingly, nearly half of neurologists say it's time – there's simply not enough during most consultations. But patients hold a different view, saying the greatest obstacle is not wanting to be perceived as being “difficult,” followed by time constraints.



NEUROLOGISTS: NOT ENOUGH TIME

NEARLY HALF of neurologists say there's simply not enough time during most consultations



PATIENTS: BEING “DIFFICULT”

Greatest obstacle is not wanting to be perceived as being “difficult”

“Is this a true disagreement? It's not that patients don't see time constraints as an issue; they just don't rank it as doctors do. We don't have to agree on what the biggest difficulty is – we should address all issues identified by both sides. Also, patients might not volunteer symptoms without specific questions. It might help for physicians to ask a leading question, such as, ‘Is there anything else you'd like to ask me?’ We know that in sensitive areas, we often need to bring up questions first.”



Martin Duddy, M.D.
United Kingdom

“Time with patients, or a lack thereof, affects disease management. Some of the more personal topics that come up – like work, family and sexuality – depend on how much contact you have with a patient. If doctors are able to spend only a short time with a patient, I think they're more biased to look at physical symptoms, like motor issues, and not so much on less obvious symptoms such as cognitive problems.”



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

“Another nuance I think is true is not wanting to disappoint your doctor. There's a prevailing concept that we live in a world where you should be able to manage your condition, as if it's a matter of mind over body. When people report their symptoms, they may feel they're letting themselves and their doctor down. Of course, that couldn't be further from the truth. And because of the fluctuations of MS, if they see their doctor on a good day, they may downplay the couple of bad days they had a week ago.”



Maggie Alexander
European Multiple Sclerosis Platform

TOP FINDINGS BY COUNTRY

From food to language to healthcare, much of how we experience life depends on the country and culture we're living in. So it makes sense that MS patients and treating neurologists from various nations perceive MS care – and communication between clinicians and patients – from different perspectives.

What other cultural factors impact MS care and doctor-patient communication?

“In Spain, 73 percent of MS patients felt the disease had a lot of negative impact on their lives. Finding a job here is clearly more difficult than it was even five years ago, so the social support these patients are receiving has decreased as well. For people who are more disabled, it's more difficult to find any other support apart from family. Another possible barrier to communications – and this is true overall – is that the majority of neurologists are middle-aged men and majority of patients are younger women.”



Mar Tintore, M.D., Ph.D.
MS Centre of Catalonia, Spain

“In Germany, MS patients were in a much worse situation 25 years ago, when I started practicing. There was a greater incidence of divorce and family problems. Now there's more awareness about MS, which has improved overall care a great deal. Most of the time, people stay together even if one of the partners has MS and proactively find accessible housing and other means of support.”



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

“In the United States, our healthcare system imposes all sorts of requirements on neurologists that aren't related to giving MS care, such as tending to electronic medical records and counseling patients on obesity and colonoscopies. This is really outside the scope of what we do, and yet it consumes a great deal of our time and poses a challenge to improving communication with patients.”



David Jones, M.D.
United States

The State of MS survey made clear just how striking these country and cultural differences really are. **Some of the most compelling findings indicate:**

MS PATIENTS IN THE U.S.

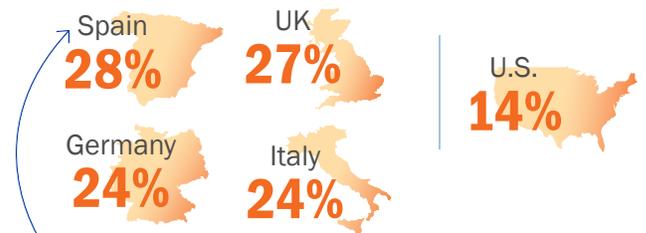
are much more likely (47 percent) to **say their health is excellent or good** compared to their counterparts in:



Italy 26% | Germany 21% | UK 17% | Spain 11%

EUROPEAN PATIENTS

are most apt to report that **not wanting to be seen as a “difficult” patient** interferes with their communication with their neurologist compared to those in the U.S.:



PATIENTS IN SPAIN are also most likely (30 percent) to say they **hesitate to ask questions** compared to:

Italy 15% | UK 13% | Germany 11% | U.S. 10%

IN GERMANY AND SPAIN, patients report the most difficulty discussing typical MS symptoms such as:



NEUROLOGISTS IN ITALY

are least satisfied with their communication with patients about available support options

IN THE UK patients are the **most apt to say they're VERY UNCOMFORTABLE**

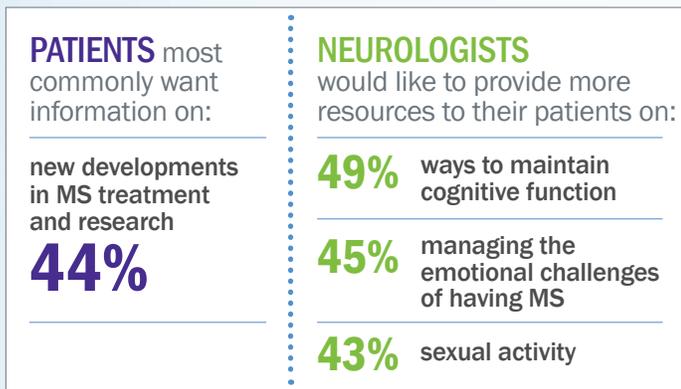
talking to their neurologist about their MS.



But nearly three-quarters of patients in the U.S. report being **VERY COMFORTABLE** speaking to their neurologist about their MS.

PROVIDING AND PACKAGING INFORMATION IN WAYS THAT MATTER

Plenty of information about MS is out there, and it's relatively easy to find. But that doesn't mean patients and neurologists aren't looking for more information on certain aspects of the disease.



Opinions also sometimes differ on the best sources of information. While 63 percent of neurologists recommend materials available at their office, only 19 percent of patients identify these materials as being most helpful to them.

Patients and physicians, meanwhile, are utilizing social channels for information. Nearly three-quarters of patients (72 percent) and neurologists (73 percent) say online and social media resources are most helpful for finding information about MS.



How can information be packaged in different ways to resonate with both physicians and patients?

“There’s so much information already on the Internet and in books, which makes it difficult to know the new thing that will be attractive in terms of doctor-patient communication. I think we need to explore more communication between patients, because many times patients trust a peer. We should do this more in MS, though it’s challenging to pair patients with similar disease courses.”



Mar Tintore, M.D., Ph.D.
MS Centre of Catalonia, Spain

“The temptation is to produce easy paper information sheets, whereas patients are looking for face-to-face communication and good online resources. That’s something physicians have been weak in offering. Should we be filtering online information, or perhaps curate it from reliable sources? That would require a considerable ongoing effort and may be more effective if done nationally instead of locally.”



Martin Duddy, M.D.
United Kingdom

“More than anything, I would expect the most reliable information to arise from MS centers, advocacy groups and general health websites. I was particularly happy to see that in this specific aspect, Italy performed very well. For neurologists, I think scientific literature should be their primary source of information, but it’s not always that accessible or easy to read.”



Antonio Uccelli, M.D.
Italy

“More than 40 percent of MS patients in the survey were in a younger age group, under age 45. These are social media people – they’re going online and are not as likely as older patients to read material from a doctor’s office. So I think our job is to provide them with a list of reliable websites we feel they should use.”



Sibyl Wray, M.D.
United States

CONCLUSION

A positive outlook plays an important role in helping to cope with the many challenges of MS. So we're pleased that the global State of MS survey has revealed that most patients and neurologists view overall MS care – and especially conversations between them – in a favorable light. They feel comfortable with each other, which is surely the foundation of a mutually beneficial partnership.

But it's concerning that both sides of this partnership sometimes hold back from discussing certain MS symptoms, even those characteristic of the disease. What they *do* talk about may differ significantly from what they *want* and *need* to talk about. Also at odds is the type of information doctors and patients are seeking about MS and where they expect to find it. These gaps in communication desperately need to close.

As State of MS Consortium members, it's our distinct privilege to educate and enlighten the global MS community about this comprehensive survey. We hope to take advantage of what's been learned to help neurologists and patients align expectations, confidently approach sensitive issues and find information from the most reliable sources.

This survey was ultimately designed to enhance MS patients' lives all over the world. We hope patients and neurologists will use the findings to uncover new tools, resources and communication methods to deepen doctor-patient dialogue.

– The State of MS Consortium