

# OPTIMIZING COMMUNICATION IN THE EVOLVING MULTIPLE SCLEROSIS BENEFIT:RISK LANDSCAPE

A position statement from the Navigating MS Steering Committee



# Optimizing communication in the evolving multiple sclerosis benefit:risk landscape

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## Executive overview

Disease-modifying therapies (DMTs) present an opportunity to optimize disease management for individuals with multiple sclerosis (MS). However, the myriad of treatment options available and absence of consensus treatment protocols may result in ambiguity around how to select the best treatment strategy in the face of an uncertain disease progression pattern. Furthermore, the benefits and risks of DMTs need to be appropriately understood and assessed by all involved.

Navigating MS is an initiative designed to improve outcomes for people with MS through the global adoption of strategies that optimize therapeutic decision-making. The first Navigating MS conference was held in June 2016 to develop a global expert position statement on effective communication and shared decision-making between people with MS, their care partners, and healthcare professionals (HCPs).

Shared decision-making is an approach where clinicians and patients share the best available evidence when considering treatment options, with a goal of achieving informed preferences. This involves examining possibilities, risks, uncertainties, and options, then comparing them and determining a course of action. However, there are challenges to this kind of communication in clinical practice, including: lack of understanding of a shared decision-making approach; time/resource constraints; difficulty for the individual with MS accessing the clinic due to geography or disability; lack of disease understanding on the part of the individual with MS; different expectations between the individual with MS, their care partner(s) and the HCP; and lack of current MS treatment knowledge on the part of the HCP. Finally, best practice for communication is likely to differ depending on the cultural values and expectations of the individual with MS.

Any conversation about the benefits and risks of DMT treatment in MS needs to involve a demonstration to the affected individual on how treatment can modify the disease course and ensure that treatment goals are aligned between the patient, care partners, and HCP. Setting of mutually agreed goals and desired outcomes needs to be individualized and fully understood by the HCP and the person with MS.

Recommendations for optimizing conversations about benefit:risk in MS include effectively engaging the person with MS, using techniques such as patient decision aids, health coaching, question prompts, and education. Health literacy is a fundamental component of patient engagement and can be facilitated by using personalized information, providing access to telephone counseling or helplines, guiding access to social media and relevant websites, and motivational interviewing. Individualizing communication will likely improve success. It is also important that the most effective ways to communicate with care partners and other members of the HCP team are considered.

The Navigating MS group believes that health outcomes can be improved by transforming the individual with MS into an active partner in their healthcare management through a clearer understanding of their disease, more effective communication with the healthcare team, and a shared decision-making approach to treatment. To achieve this goal, the Navigating MS group will identify barriers to effective communication and develop strategies to improve communication with people with MS on a global level. The hope is that this change will improve health outcomes for all individuals living with MS.

## Introduction

Multiple sclerosis (MS) is a chronic inflammatory condition of the central nervous system and one of the most common causes of non-traumatic neurologic disability in young adults. Estimates from 2012 suggest that approximately 400,000 people in the United States (US)<sup>1</sup> and 2.3 million people worldwide<sup>2</sup> have MS, with a significant regional variation in prevalence. Many people with MS will eventually develop ambulatory dysfunction requiring an assistive device to maintain mobility. In addition, the “silent symptoms” of the disease (i.e., cognitive challenges, fatigue, pain, and depression) are disabling and frequently cause affected individuals to leave the workforce earlier than expected.<sup>3</sup> The economic impact of MS is staggering,<sup>4,5</sup> with the annual cost of the disease in the US estimated at \$28 billion.<sup>4</sup>

Before 1993, MS care was limited to correct diagnosis of the disease and management of symptoms through the use of rehabilitation, coping strategies, and/or medications. Since that time, over a dozen disease-modifying therapies (DMTs) have been approved for relapsing forms of MS based on their ability to reduce the frequency and severity of relapses, reduce new magnetic resonance imaging (MRI) lesions and thereby likely delay the progression of disability. Furthermore, the first DMT for treatment of primary progressive MS has recently been approved by the US Food and Drug Administration.

Early intervention is key to maximizing brain health and physical function in MS.<sup>6</sup> There is strong evidence supporting the importance of early DMT treatment and symptom management for both short- and long-term health outcomes in individuals with relapsing MS.<sup>7-13</sup> In addition, a 21-year follow-up of a randomized controlled trial (RCT) comparing interferon beta-1b with placebo found that mortality was reduced by 46–47% in the group originally assigned to active treatment,<sup>14</sup> indicating that not treating MS with DMTs increases the risk of death. The higher death rate in the placebo-treated group was largely attributed to MS-related causes.<sup>15</sup>

The evolution in MS care afforded by DMTs presents an opportunity to optimize disease management for individuals receiving a new diagnosis, those with an active relapsing disease course warranting highly effective therapy, and for those whose disease has already advanced. However, these treatments are also associated with increased risk of adverse events,<sup>16</sup> which needs to be appropriately understood and assessed by all involved.<sup>16-18</sup> Furthermore, the myriad of treatment options available and absence of consensus treatment protocols challenge the overall management of MS for the affected individuals, their care partners, and healthcare providers (HCPs). Indeed, the number of untreated or undertreated people with MS suggests that there is a knowledge gap in understanding the risk posed by the disease itself. This therapeutic inertia may relate to ambiguity around how to select the best treatment strategy in the face of an uncertain disease progression pattern. Furthermore, some of the cornerstones of MS care (especially treatment of relapses, symptom management, rehabilitation, and wellness) can sometimes be relegated to secondary importance relative to DMT treatment, potentially increasing the functional impact of MS.

## The Navigating MS initiative

Navigating MS is an initiative designed to improve outcomes for people with MS through the global adoption of strategies that optimize therapeutic decision-making. While it is difficult to succinctly define optimal care in MS (Box 1), one of the keys to providing such care is to understand the benefits and risks associated with treating the disease. Furthermore, we need to be able to interpret these benefits and risks at the level of the individual patient and have the tools to discuss these in a shared decision-making environment. In an optimal therapeutic relationship, both the individual with MS and the HCP should feel comfortable with the decision achieved.

### **Box 1. Defining optimal care in MS**

Human beings are unique, not only because of differences in their genetic disposition and the summation of environmental influences that have predisposed and altered their biology, but also because of their psyche, their personal experiences and relationships, their values, and their hopes and dreams. Indeed, the psychological make-up of an individual may be as complex as his/her biological make-up. One could also argue that biology can affect the psychology of a person (and vice versa), especially in diseases that affect the brain. For this reason, development of treatment algorithms for a heterogeneous, chronic, and potentially debilitating neurologic disease like MS will never allow a “one size fits all” approach. Treatment plans for MS should be tailored to holistically target the individual’s needs and desires.

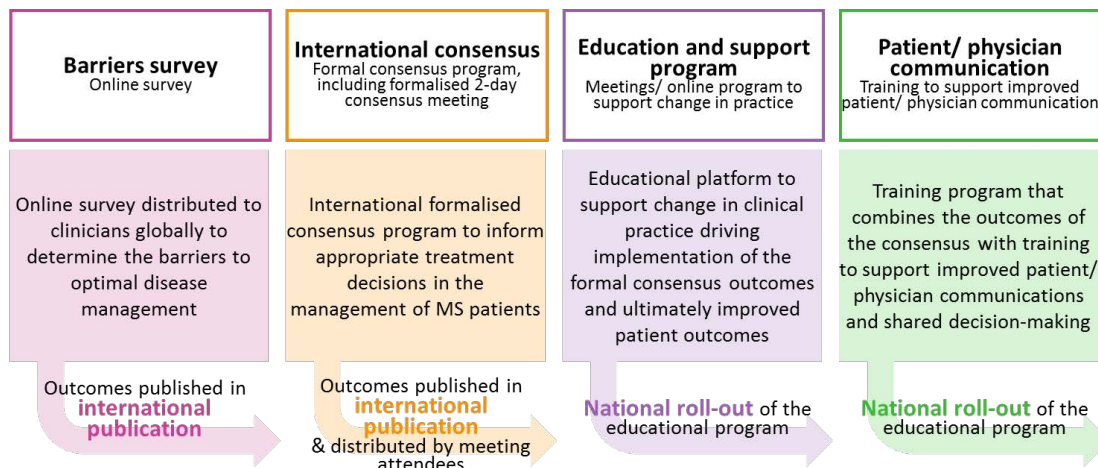
Optimal care of a person with MS is easier to accomplish if that individual remains at the “center of the circle” and is considered by all as a “person who lives with MS” and not an “MS patient”. Effective communication and a desire to understand the individual’s disease process, beliefs, values, goals, and fears (and perhaps those of their care partner) are paramount in shared decision-making. When discussing an individual’s MS disease course and its associated impact, it is important to balance authenticity, realism, and optimism to ensure that the individual is appropriately educated about their disease and able to participate as much as they wish in tailoring their MS care plan. Obviously, the development of a treatment plan should respect the individual’s goals and risk tolerance. Shared decision-making should improve the individual’s adherence to the treatment plan and perception of the outcome. The therapeutic benefit of a quality relationship is demonstrated in MS RCTs in which the placebo group often reaped a therapeutic benefit despite not receiving a pharmacologically active medication.<sup>19</sup>

The treatment plan must consider modification of the disease process, management of the patient’s symptoms, and acknowledgment of related psychosocial concerns. Too often, there is discordance between the HCP and person with MS regarding priorities. Comprehensive care requires an interdisciplinary team (IDT) or multidisciplinary team (MDT) approach, which facilitates coordination of services and continuity of care.<sup>20</sup> The team approach places the person with MS at the center of the team and includes HCPs specializing in MS, such as a neurologist, advanced practice clinician (APC), nurse, primary care provider, urologist, ophthalmologist, mental health professional, rehabilitation professional, social worker, and dietician.<sup>21</sup> Wellness and management of comorbidities are also essential to achieve optimal outcomes.

An important aspect of optimal MS care is careful surveillance of ongoing disease activity and related symptoms. Evidence of breakthrough (either clinical or radiographic) disease or a worsening functional status may alter a person’s treatment goals and risk tolerance, and will likely warrant changes in the treatment plan. Just as MS changes over time, a person’s treatment plan may change over time; however, the tenets of effective communication, shared decision-making, and an emphasis on the entire individual likely remain priorities.

The first Navigating MS conference was held in June 2016 to develop a global expert position statement on effective communication and shared decision-making between people with MS, their care partners, and HCPs. The meeting was attended by over 35 HCPs (including MS neurologists, MS ACPs, MS nurses, physical therapists, and neuropsychologists) and representatives from advocacy organizations for people with MS in the US, EU and Australia. While there were wide differences in culture and healthcare systems between regions, there was broad consensus that much work is needed to improve and support the ways that HCPs discuss disease management with individuals with MS and their care partners. Specifically, the need to improve the ways that MS HCPs communicate the benefits and risks of existing treatments (relative to each other and within the context of the risks posed by suboptimal disease management) emerged as a critical issue.

The immediate focus of Navigating MS is to better understand some of the existing barriers to optimal treatment, together with the current landscape of resources available to assist decision-making. Initial efforts have prioritized effective communication around the benefit:risk paradigm to inform and enhance shared decision-making between HCPs and individuals with MS. Ongoing work of this group is focused on the development of a survey to be distributed to MS HCPs in order to identify barriers to optimal disease management. In parallel, this group is also compiling a list of existing global resources aimed at improving the way that people with MS, their care partners, and HCPs talk about disease management and treatment decisions. Addressing this knowledge gap will identify useful materials that may be shared more broadly. The next phase of Navigating MS will involve developing tools and educational interventions that are tailored to address the identified barriers to create a lasting change in MS clinical practice (Figure 1).



**Figure 1. What might the future of Navigating MS hold?**

The Navigating MS Steering Committee has developed this global expert position statement on effective communication and shared decision-making to guide fully informed treatment decisions in MS.

## Recognizing the opportunity to optimize the management of MS

MS is a highly heterogeneous disease, with some individuals accruing disability very rapidly and others having a seemingly benign form (at least on disability scales). Different clinical phenotypic (relapsing, secondary progressive, and primary progressive), immunologic, and pathologic subtypes of the disease have been identified, as have over 200 different genetic loci that increase the risk of this disease. Given this heterogeneity, it is reasonable to conclude that treatment of MS is not a “one size fits all” approach.

It is clear in clinical practice that response to treatment varies greatly among people with MS; however, there is currently a lack of consensus to guide DMT selection. In this era of evidence-based medicine, clinicians may be required to cite evidence to support treatment plans, although the initial tenets of evidence-based medicine did not suggest that a lack of evidence was an excuse for therapeutic inertia or nihilism.<sup>22</sup> Historically, many of the clinical trials supporting the use of DMTs in MS have been comparisons with a placebo rather than an active treatment; therefore, there is a significant need for high-quality comparator trials to prioritize DMTs based on efficacy and safety. Further, the diagnostic criteria for MS have changed several times since the first DMT was approved, and definitions of suboptimal response and guidelines regarding DMT switch are not well developed. Additionally, patients treated in real-world clinical practice are often different to those represented in clinical trials, challenging the treatment dynamic. Finally, economic decisions regarding access to a particular DMT often intercalate into clinical decision-making when evidence is lacking, further degrading the impact of clinical acumen.

Given the aforementioned factors, decisions on which DMTs to offer to a particular person with MS can be challenging. DMT choices that prioritize safety over efficacy are typically made in the first-line setting, with the expectation that a more efficacious DMT can be considered if there is break-through disease activity; however, this escalation paradigm may miss the optimal therapeutic window for preventing or delaying disability. In the setting of a significant burden of disease, or other prognostic or risk factors for poor outcomes, the early use of a highly efficacious (but with potentially more serious adverse events) DMT can be considered in order to reduce disease progression, perhaps followed by a safer agent to maintain remission (induction paradigm); however, the possibility of rebound disease after stopping the highly efficacious agent needs to be considered.<sup>23-25</sup> For this reason, some individuals may continue with a more intensive DMT regimen indefinitely.

Ideally, a person with MS and his/her clinician would be able to definitively determine the “right medication at the right time” – a concept referred to as “personalized medicine”. Much of the discussion around personalized medicine focuses on scientific concepts like disease biomarkers, proteomics, microRNAs, pharmacogenomics, and pharmacometabolomics. However, other aspects such as culture, education background, social role, expectations, language/communication styles, disease perceptions, and risk tolerance are also important in clinical decision-making. These differences can affect acceptance of the disease, willingness to initiate a DMT, and adherence to the prescribed treatments. Consideration of the person’s background and MS disease state characteristics should be factored into therapeutic decision-making. Indeed, the essential tenets of medicine, such as good communication skills, respect for people, beneficence, and caring are timeless, as are the HCP’s eyes, ears, words, and “heart”. Arguably, the application of these tenets has therapeutic benefit, even in the absence of correct science or proven treatments.

Optimal DMT treatment initiation and switching requires an objective and patient-centric conversation between the HCP and the person with MS. Engaging the person with MS throughout their healthcare journey is key to treatment satisfaction, adherence and self-empowerment; these in turn significantly contribute to self-efficacy and autonomy. One paradigm for this is shared decision-making – a skill that can (and arguably should) be learned by both HCPs and patients. Shared decision-making is a collaborative process that requires involvement of both the HCP and the patient, although it may also include other

members of the healthcare team and family or caregivers.<sup>26</sup> This type of interaction involves open discussion and sharing of information: typically, the HCP offers different therapeutic options with consideration of their respective benefits and risks, while the patient expresses his/her values and preferences. All parties take some responsibility for the decision made. A shared decision-making approach may have particular impact in the context of MS, with a recent survey indicating increased DMT satisfaction for people with MS who were able to provide input into their treatment plan.<sup>27</sup>

## Understanding the challenges to the optimal management of MS

The uncertainty surrounding the course of MS often poses a significant amount of distress to the affected individual and his/her family. Effective communication is an integral component of the relationship between the HCP and the person with MS. This communication forms not only the basis for building rapport, but is also the platform from which patients may begin to play an integral part in collaborative decision-making regarding their disease. Indeed, the State of MS initiative, which was a survey including responses from 982 patients and 900 neurologists from the USA and Europe, showed that good communication between the person with MS and their HCP is a crucial aspect of optimal MS care.<sup>27</sup>

However, there are a number of challenges to effective communication in clinical practice (Box 2). Time and resource constraints are often cited as barriers to the HCP being able to fully engage with people with MS and their care partners. In the State of MS survey, almost half of the neurologists identified the lack of sufficient time as the most important impediment to effective communication.<sup>27</sup> Certainly, the electronic medical record (EMR) can interfere with quality communication in the clinic, especially non-verbal communication. Time constraints may mean that the person with MS is not able to participate in IDT meetings regarding their care, and financial constraints or health system formularies may alter or limit access to the treatment plan deemed most appropriate by the person with MS and their HCP. To add complication, there are often months between appointments with a member of the healthcare team, and some individuals (particularly those in rural locations) may experience difficulty in traveling to their clinic appointments.<sup>26</sup>

Arguably, the simple concept of putting the person with MS at the center of the therapeutic circle should lead to improved engagement and better outcomes; however, this approach remains challenging in clinical practice. First and foremost, both the person with MS and the HCP need to be comfortable with this arrangement. The degree to which an individual engages in and takes responsibility for their own treatment varies according to personality, culture, education, family support, and rapport with their HCP. In the State of MS survey, almost one quarter of people with MS indicated that the reason for suboptimal communication with their HCP was the fear that they would be viewed as a difficult patient.<sup>27</sup> It is possible, however, that this is also an effect of time availability, as the fear of being a difficult patient may be linked to the fear that the HCP would not be willing to dedicate sufficient time to exploring their concerns. This highlights the importance of ensuring that the person with MS and their care team are familiar with the concept of shared decision-making and understand that this approach is being applied to their interactions with their HCPs.

Furthermore, it is important for the person with MS to understand the information about their disease and its treatment, so that they can formulate or articulate their preferences and treatment goals. Individuals with MS may not come to their clinic visit with an understanding of the trade-offs between the benefits and risks of treatment, the risks of non-treatment, or the reality of their disease progression. Cognitive dysfunction, a common disabling symptom of MS, may also impair the ability of the individual to fully understand and process complex information. Benefit:risk analyses of different DMTs are often challenging, especially in individuals who are not adept in judging probabilities or those who experience difficulties in processing or retaining information. The benefits of DMT treatment mainly relate to preventing a future occurrence (e.g. relapse, progression) and are more conceptual (and hence more difficult to grasp) than the risks of treatment (e.g. side effects), which are more concrete and short term. The risks of MS progression



can be difficult to predict accurately, so authenticity and optimism need to be carefully balanced. It is important to also clearly manage expectations around the chosen treatment, as DMTs are not intended to improve symptoms. While the HCP's definition of "living well" may differ from that of the person living with MS, the role of symptomatic management and wellness should never be forgotten. Health beliefs also play a role in therapy choice. Some patients choose complementary therapies or diets to augment their pharmacological therapy, and others forego the latter to pursue alternative approaches to disease management.<sup>28</sup>

People with MS may also have family members or support partners with strong opinions regarding the risk of the disease progression and the benefits:risks of treatment. Like the person with MS, the care partner may also be more concerned about symptomatic management than disease modification. It can be particularly challenging when care partners have different goals or risk tolerances than the person with MS. Aligning these expectations can potentially be difficult.

Lack of up-to-date knowledge on the part of the HCP may also result in incomplete or ineffective communication, as the landscape of MS treatment options is rapidly changing and becoming increasingly complex. There may be differences between HCPs in the terminology used to describe risks and benefits. The ability to assess and verify whether the person with MS understands the risk and benefits of treatment may also vary between HCPs, and taking the time to ensure that this is well understood may also be a problem.

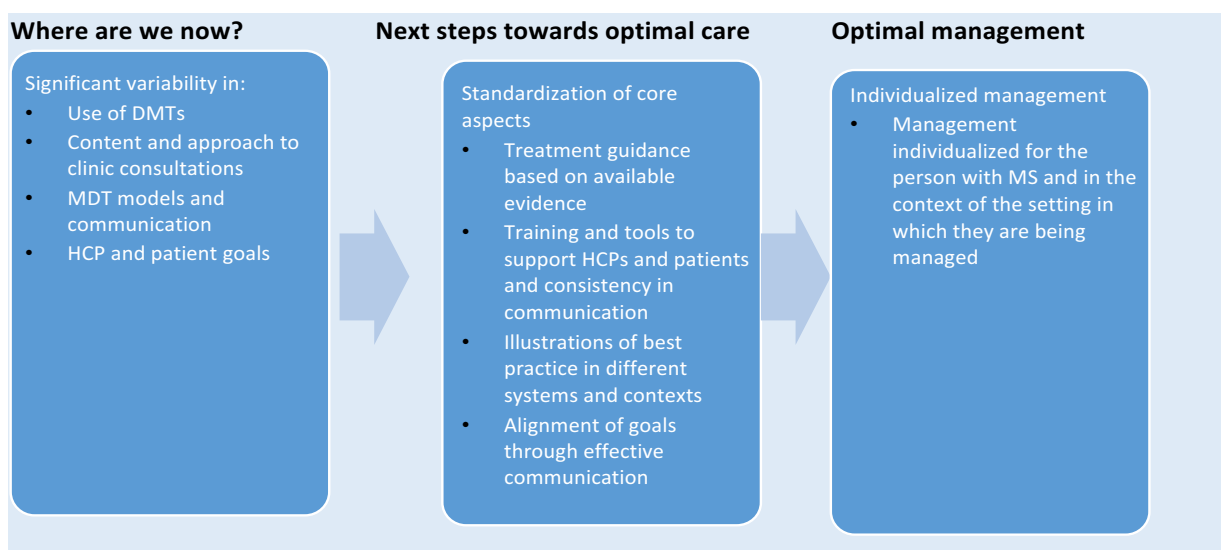
Finally, best practice for communication between individuals with MS and HCPs is likely to differ, depending on cultural values and expectations. This makes it difficult to standardize consistency in communication across different regions and countries.

**Box 2. Challenges to effective communication in MS clinical practice**

- Lack of mutual understanding of the shared decision-making approach
- Time constraints
- Resource constraints
- Difficulty for the individual with MS accessing the clinic due to geography
- Lack of disease understanding on the part of the individual with MS
- Different expectations between the individual with MS, their care partner(s) and the HCP
- Lack of current knowledge of the part of the HCP

## Navigating MS: What is the opportunity?

Currently there is significant variability in the treatment and management of MS. While optimal care includes alignment of the treatment goals of the person with MS and their HCP through an IDT or MDT, this is not always the reality. A significant evolution in the approach to management of MS is required (Figure 2). The Navigating MS initiative seeks to standardize some of the core aspects of optimal care through developing interventions that help illustrate best practices in effective communication and lead to improved health outcomes for the person with MS.



**Figure 2. Significant evolution in the approach to the management of MS is required in the advent of new therapies.**

## Focusing on communicating benefit:risk considerations to inform shared decision-making

### Shared decision-making – what is the evidence?

Shared decision-making has been named the “pinnacle of patient-centered care”<sup>26</sup> and is an approach where clinicians and patients share the best available evidence when considering treatment options, with a goal of achieving informed preferences.<sup>29,30</sup> This collaborative communication enables patients to feel supported and enhances trust within the HCP–patient relationship. It therefore leads to a higher likelihood of agreement on disease outcome priorities, which is important for ensuring patient adherence and satisfaction. In addition, shared decision-making allows patient expectations about the disease and treatment outcomes to be better managed.<sup>31,32</sup>

There are a number of myths around shared decision-making that need to be dispelled.<sup>33</sup> It has been suggested that this approach is a fad; it leaves all decisions to patients; or, conversely, that most patients still leave decisions to their HCP; is time-consuming or too expensive; not everyone is good at it; it is incompatible with clinical practice guidelines; and that HCPs are already engaging in this approach. However, evidence does not support these presuppositions.<sup>33</sup>

The implementation of shared decision-making is a complex process with different obstacles in different settings. However, a shared decision-making approach is very useful in enhancing patient engagement in a chronic condition such as MS, where treatment is life-long but can change depending on the course of the disease, where non-pharmacological approaches are employed depending on the individual’s physical and psychological state, and where decisions related to family, employment and quality of life are necessary throughout the disease.<sup>34-37</sup>

The HCP is extremely important in the shared decision-making process. The Agency for Healthcare Research and Quality (AHRQ) has developed a five-step approach for shared decision-making (SHARE), highlighting the responsibilities of the HCP in this approach (Box 3).

**Box 3. The SHARE approach to shared decision-making**

Step 1: **Seek** your patient's participation.

Step 2: **Help** your patient explore and compare treatment options.

Step 3: **Assess** your patient's values and preferences.

Step 4: **Reach** a decision with your patient.

Step 5: **Evaluate** your patient's decision.

Adapted from the Agency for Healthcare Research and Quality. Available at:

<https://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/tools/tool-1/index.html>

### Discussing benefit:risk with patients – what are the considerations?

Communicating benefit and risk is not solely about imparting information, but about engaging with the person with MS and their care team in a mutual learning process<sup>38</sup>. In MS, benefit:risk discussions often take place in the context of decision-making regarding specific DMTs. This approach not only has limitations in terms of time, but also fails to address MS as a whole entity. The discussion of the risk of the disease itself in the absence of treatment (e.g. progression, relapses, effect on quality of life, employment and cognitive function) or the risks of undertreating the disease may often be incomplete or neglected altogether.

Decision-making is a process of examining possibilities, risks, uncertainties, and options, then comparing them and determining a course of action. Individual risk tolerance – that is, the individual's willingness to accept an increased likelihood of adverse events or negative events in exchange for better health outcomes – is an important part of this equation. There may be considerable differences in risk tolerance between people with MS and their HCP. Surveys consistently show a higher patient acceptance of risk of adverse outcomes of treatments in exchange for higher efficacy.<sup>39,40</sup> Risk tolerance is multifactorial and dynamic,<sup>40</sup> and effective conversations about benefits and risks of MS treatment need to take these factors into account.

Any conversation about benefit:risk needs to involve a demonstration to the individual with MS on how treatment can modify the disease course and ensure that treatment goals are aligned between the affected individual, care partners, and HCP. There is substantial heterogeneity in neurologists' approaches to MS treatment, knowledge, resources, and risk perception and acceptance. Heterogeneity between people with MS relates to disease characteristics, personality features, and experience with the disease and its prior treatment(s). Key determinants of preference for drug treatment are avoidance of serious adverse events and improvement in MS symptoms and course, which have different weights in the minds of different individuals with MS.<sup>41</sup> This means that the setting of mutually agreed goals and desired outcomes needs to be individualized and fully understood by the HCP and the person with MS.

## Recommendations for optimizing conversations about benefit:risk in MS

### Engaging the person with MS

Patient engagement is sometimes referred to as “patient activation” and has been described as the blockbuster drug of the 21<sup>st</sup> century.<sup>35</sup> This concept is defined by the US Centre for Advancing Health as “actions individuals must take to obtain the greatest benefit from the health care services available to them”.<sup>42</sup> Patient engagement promotes increased quality of service and improves health literacy, communication, and patient and team satisfaction.<sup>35</sup>

Some of the techniques used to facilitate patient engagement and shared decision-making are shown in Table 1, together with the benefits of the intervention.<sup>35,43</sup>

**Table 1. Interventions shown to support shared decision-making<sup>35,43</sup>**

<b>Intervention</b>	<b>Potential benefits of technique</b>
Patient decision aids	<ul style="list-style-type: none"> <li>Increased patient involvement in decisions</li> <li>Better understanding of treatment options</li> <li>More accurate perception of risks</li> <li>Improved quality of decisions</li> <li>Does not increase patient anxiety</li> </ul>
Health coaching	<ul style="list-style-type: none"> <li>Improved health status</li> <li>Reduces comorbidity/mortality</li> <li>Minimizes risk factors</li> </ul>
Question prompts	<ul style="list-style-type: none"> <li>Increased question asking in consultations</li> <li>May increase patient knowledge and understanding</li> <li>May empower patients and improve satisfaction</li> <li>Does not necessarily increase length of consultations</li> </ul>
Self-management, education and support	<ul style="list-style-type: none"> <li>Improved patient knowledge and understanding</li> <li>Improved confidence and coping ability</li> <li>Improved health behaviors</li> <li>Improved social support</li> <li>May improve adherence to treatment recommendations</li> <li>May improve health outcomes</li> <li>May reduce hospital admission rates</li> </ul>

## Improving health literacy

The importance of health literacy in patient engagement is fundamental. Several studies have shown that education and provision of information or decision aids improve decision autonomy, knowledge and satisfaction with care in MS.<sup>34,44-46</sup> There are several strategies to increase health literacy.

**Personalized information** can be provided in paper or electronic form and reinforced by the HCP and lay support, including relevant patient organizations. This results in improvement in patients' knowledge and understanding of their disease, an increased sense of empowerment, greater ability to cope with the effects of illness, and improved satisfaction. This may lead to improvements in health behavior and better health outcomes.<sup>35</sup>

### Using personalized information to convey benefit:risk in MS

One of the key elements of a conversation about benefit:risk in MS is showing the individual with MS how treatment can modify the disease course. This can be accomplished in several ways, including using MRI scans (including the individual's own scans if possible) to demonstrate how DMTs reduce disease activity, correlating MRI changes with symptom scores, or using videos to show improvements in walking quality with symptomatic management.

A very effective method for visualizing the risk of a negative outcome of a disease or a treatment is the use of Paling palettes ([www.riskcomm.com](http://www.riskcomm.com)). These visual aids, which can be used to demonstrate the probability of different events occurring, were developed specifically for risk communication in various healthcare settings, although these are not in published papers in MS to date.

Illustration of risk can also be performed by comparing similar risks for certain events. For example, the risk of progressive multifocal leukoencephalopathy (PML) with natalizumab may be compared with the risk of being injured in a major car accident (approximately 1:1000),<sup>40</sup> (bearing in mind that this risk increases in individuals with John Cunningham virus [JCV] antibodies or with prior immunosuppressant use).

Regardless of the method, it is important to provide assurance to individuals with MS that there are numerous ways in which informational material can be provided and tailored to their needs, resources, and circumstances.

**Telephone counseling and access to various helplines** can help answer questions in a timely manner, reducing anxiety and increasing patient empowerment. The availability of telephone counseling can also reduce social isolation and may contribute to improved health status and better quality of life.<sup>35</sup>

### Use of counseling to facilitate benefit:risk understanding in MS

Knowing oneself improves confidence with healthcare decision-making. Appropriate counseling may empower the individual with MS to recognize and then prioritize their values. In turn, this realization may help to shed light on the individual's comfort level with the benefits and risks of MS management strategies.

**Access to social media and relevant websites** provides individuals with MS with a vast array of resources, albeit not all reliable or conducive to positive forms of communication. Nevertheless, social media plays an integral role in many patients' decision-making processes and often forms the basis for their opinions regarding benefit:risk. One survey found that 82% of patients went online prior to their appointments with their neurologist, but only 36% discussed those findings with their HCP.<sup>47</sup> Channeling appropriate and useful forms of electronic resources should be discussed with the person with MS.<sup>48</sup>

#### **Websites with useful information for individuals with MS and their care partners**

- Multiple Sclerosis Association of America ([www.mymsaa.org](http://www.mymsaa.org))
- National MS Society ([www.nationalmssociety.org](http://www.nationalmssociety.org))
- Multiple Sclerosis Foundation ([www.msfocus.org](http://www.msfocus.org))
- Multiple Sclerosis Brain Health ([www.msbrainhealth.org](http://www.msbrainhealth.org))
- Multiple Sclerosis Trust ([www.mstrust.org.uk](http://www.mstrust.org.uk))
- Multiple Sclerosis Decisions (<https://www.mstrust.org.uk/understanding-ms/ms-symptoms-and-treatments/ms-decisions>)
- Multiple Sclerosis Society of the UK and Northern Ireland ([www.mssociety.org.uk](http://www.mssociety.org.uk))
- Multiple Sclerosis Australia ([www.msaustralia.org.au](http://www.msaustralia.org.au))
- European Multiple Sclerosis Platform ([www.emsp.org](http://www.emsp.org))\*
- Multiple Sclerosis International Federation ([www.msif.org](http://www.msif.org))\*
- Shift MS ([www.shift.ms](http://www.shift.ms))
- Can Do MS ([www.mscando.org](http://www.mscando.org))
- Barts MS Blog ([www.multiple-sclerosis-research.blogspot.com](http://www.multiple-sclerosis-research.blogspot.com))
- MS Living Well ([www.mslivingwell.org](http://www.mslivingwell.org))
- Neurology Care ([www.neurologycare.net](http://www.neurologycare.net))

\*Contact these organizations for information about non-English-language MS websites.

**Motivational interviewing** is a specific patient-centered counseling technique regarding change that can be utilized by all members of the healthcare team. Motivational interviewing promotes adherence to treatment and exercise programs, behavior change and lifestyle modification.<sup>49,50</sup>

#### **Motivational interviewing techniques applied to shared decision-making**

One of the central processes in shared decision-making is to elicit the individual's perceptions about their current situation and then to help them explore and voice their own concerns and reasons for change. This approach can be more effective than telling the individual what to do.

O.A.R.S is a skills-based model of interactive techniques using motivational interviewing principles.<sup>51</sup>

- **Open-ended questions** – to build rapport, allow the HCP to understand their patient's world, and gather information.
- **Affirmations** – verbal statements and non-verbal gestures to demonstrate empathy, affirm achievements, and build self-efficacy.
- **Reflective listening** – short statements to show the patient that the HCP is listening and understanding, and to allow the patient to confirm, adjust, or elaborate on the statement.
- **Summarizing** – re-emphasis of pertinent points, allowing the HCP and patient to move through a session to transition and closure.

## Ensuring that patients are fully informed

With increasing complexity of available MS treatment options, it is essential to ensure that the benefit:risk information provided to the person with MS is complete and has been understood. It is advisable to review the key points of the conversation with the individual and their care partner.

Some individuals may decline treatment despite their HCP's opinion that it may be beneficial, leading to a potential conflict between the ethical principles of respecting autonomy and non-maleficence.<sup>52</sup> In such cases, continued clinical and radiographic follow-up should be offered.

It may be helpful to encourage people with MS to network with patient groups to share experiences, either in person or online (e.g. [www.shift.ms](http://www.shift.ms)). Although opinions among group members can be diverse, the person with MS may derive significant reassurance and better understanding of risk and disease progression from interactions with other affected individuals. However, people with MS should be reminded that the health information provided in a peer-to-peer setting may be inaccurate. Furthermore, potential conflicts of interest from the sponsors of on-line forums should be considered.

## Maximizing effectiveness and available time of consultations

Ideally, both the HCP and the person with MS are prepared for the appointment and time is protected at the start of the consultation to prioritize key discussion points. Patients should be encouraged to come to the consultation with goals or concerns to discuss. This may involve providing the patient with homework/pre-reading. Resources such as quality of life questionnaires, risk perception questionnaires, and symptom management tools can also be useful for identifying the patient's current priorities, setting the expectation of the consultation, and utilizing the available time productively. The HCP's agenda needs to be adaptable to their patient's current needs, ensuring that the person with MS feels validated and that their concerns are important. The EMR may facilitate communication during the consultation by allowing information (e.g. images, laboratory results, or notes from other clinic visits) to be readily available.

Simple interventions such as greeting the person with MS (and their care partners) and asking about their specific concerns at the beginning of the consultation may decrease the total time of the consultation, as this builds rapport and develops a stronger therapeutic partnership. This may involve asking the person with MS: "What shall we discuss today?" or ending the conversation by asking: "Is there anything else that you would like to discuss?"

Multiple consultations are required for effective MS management. There is no current consensus on the appropriate timeframe for a scheduled consultation between an HCP and person with MS. Short and more frequent visits may help the person with MS process the information that they have been given, but consultations that are perceived as "rushed" may leave the individual feeling lost or disempowered. However, the circumstances of a given individual will likely contribute to the most appropriate length of consultation; for example, a person with MS who lives far from the clinic may be better served by fewer but longer and more comprehensive appointments. In addition, involving other HCPs within the healthcare team may improve use of time in consultations and delivery of a quality service.

## Effective communication – tailored to the individual

### Effective communication with the person with MS

The goal of all communication between the HCP and person with MS is to improve and/or optimize health outcomes. However, a “one approach fits all” strategy cannot be applied when communicating with people with MS. Individualizing communication will likely improve success.

Consistent communication with the same HCP is often a priority to the patient, especially in the context of a chronic condition.<sup>53</sup> Moreover, when ongoing conversations are taking place on complex topics, such as benefit:risk, it is preferable that the person with MS has a long-term relationship with a specific HCP.

Given the complexity of benefit:risk decisions for the person with MS and their care team, having a variety of communication modes may help to ensure all questions and comments are communicated and considered by the HCP. Fundamental HCP–patient conversations typically occur within the confines of an office or examination room. However, given the frequent limitations of time in the traditional consultation setting, alternative forms of communication (such as electronic communication, telephone conversations, and telemedicine strategies) are imperative.<sup>16</sup> A study in Germany found that 90% of people with MS had access to a computer and used the internet at least once a week.<sup>54</sup> Furthermore, between 20 and 54% of survey respondents had a strong willingness, interest, and comfort with communicating via internet apps, text messaging, or e-mail. HCPs should ensure that appropriate means of communication and expected timeframes for replies are clarified with the patient (for example, the most appropriate email address on which to contact the HCP could be given to the patient). In some centers, patients may also be able to directly communicate with their HCP through an EMR portal.

### *Non-verbal communication*

Non-verbal communication is also an important consideration in HCP–patient encounters. This approach includes consideration of the environment, relative positioning of the HCP to the person with MS, acknowledgement and listening gestures, and caring non-medical touch.

Waiting areas can be used as a space/time for education and enrichment.<sup>55</sup> During the consultation, sitting at eye level or at a lower level to the person with MS may suggest a more patient-centered, shared decision-making approach to the appointment. Positioning is especially impactful given that some patients with MS may use wheeled mobility.

Non-verbal listening gestures (such as head nods, facial expressions, or eye contact) affirms delivery and internalization of the information by the HCP and helps to establish rapport and connectedness with the patient, increasing patient satisfaction.<sup>56</sup> Unfortunately, use of the EMR can contribute to inconsistent eye contact between the HCP and patient.<sup>57</sup>

Expressive touch (touch that is not part of an evaluative task or examination) includes touch of the forearm or handshake or a hug.<sup>53</sup> This can indicate empathy and humanity, although HCPs may be reluctant to engage in expressive touch owing to possible misinterpretation of intent and crossing of professional boundaries.

Table 2 summarizes some of the considerations identified by the Navigating MS group in relation to non-verbal communication.



**Table 2. Considerations for non-verbal communication with people with MS**

Factor	Considerations
Environment (waiting areas and treatment/examination rooms)	<ul style="list-style-type: none"> <li>• Easily accessible for people with limited mobility</li> <li>• Learning opportunity</li> <li>• Relaxed environment</li> <li>• Appealing to senses</li> </ul>
Relative positioning of the HCP to the person with MS	<ul style="list-style-type: none"> <li>• Position the HCP at eye level or at a lower level to the patient</li> </ul>
Non-verbal listening gestures	<ul style="list-style-type: none"> <li>• Appropriate nodding, facial expressions and eye contact</li> </ul>
Expressive touch	<ul style="list-style-type: none"> <li>• Touch of the forearm, handshake, or hug if appropriate</li> </ul>

**Effective communication with care partners**

The care partner of a person with MS can sometimes have little opportunity to express their own fears, concerns, questions, and challenges during a clinic visit. However, considering the influence that care partners have on the decision-making process, it is essential that the healthcare team communicates effectively with them.

To our knowledge, there is a lack of best practice recommendations for communicating with care partners of people living with MS.<sup>58</sup> The Navigating MS Steering Committee recommends three principles to engage care partners and improve communication:

1. Acknowledge and provide an opportunity during the consultation for the care partner to communicate their concerns or challenges.
2. Provide resources for peer and/or professional mental health support. For example, peer support groups associated with national MS organizations may be helpful, although it may be difficult for the care partner to regularly attend because of caregiving and household demands.
3. Provide consistent monitoring of the care partner’s needs as the disease changes or progresses.

**Effective communication between HCPs**

Due to the limited frequency of consultations between a person with MS and their neurologist or MS specialist, it is imperative to allow discussion of benefit:risk beyond the neurology consultation. Furthermore, as neurologists have increasingly greater demands for documentation, financial quotas, and justification with outside payers, the recruitment of other members of the healthcare team to continue and/or reinforce the message will ideally improve patient care.

Individuals with MS require a range of rehabilitative, therapeutic, cognitive and psychosocial services, according to their symptoms and disease course. This comprehensive care likely requires an IDT or MDT approach, which facilitates coordination of services and continuity of care.<sup>20</sup> While the terms “IDT” and “MDT” are often used interchangeably, there are distinct differences between these concepts.<sup>59</sup> An IDT

involves all HCPs meeting together with the person with MS in a single consultation, allowing patient-centered conversation, holistic problem-solving, and shared decision-making. Unfortunately, this arrangement may be a luxury, as members of a healthcare team are typically not all in the same physical location. In contrast, HCPs who are part of an MDT have individual consultations with the person with MS at different times (and potentially in different locations). This approach may allow the person with MS more autonomy to essentially construct the MDT that best suits their needs.

Irrespective of the utilized approach, quality communication among the team members and the person with MS is essential. All team members should be able to actively question or make suggestions on the care plan. Indeed, one of the characteristics of a good IDT is using the appropriate systems to promote communication within the team.<sup>21</sup> Often the team environment intrinsically lends itself to effective communication, but it should be highlighted that different parts of the team may use different terminology or medical language, and may have different approaches to communication. More formal communication could comprise the EMR, written care plans, standardized patient assessment, formalized IDT case meetings to discuss cases, e-messaging, and shared notetaking.<sup>54,60</sup> More traditional means of communication between HCPs include faxed reports, telephone conversations, or e-mails; however, the volume of these may be unmanageable.

Lastly, telemedicine models or video conferencing approaches are newer, evolving communication methods that allow different members of the IDT to be in different locations. This live chat/visit feature may give the person with MS access to a team regardless of their physical location, as well as limiting travel requirements that can be costly. However, this approach does require access to the appropriate technology and knowledge on how to use it effectively. Furthermore, some of the nuances of non-verbal communication may be lost. There may also be challenges regarding reimbursement for the HCP.

Regardless of the healthcare team's communication approach, the team needs a unified theme or culture. All members need to have fluid discussions with the person with MS and their care partners from their unique discipline perspective. This continuity of culture will allow key discussions to occur beyond the primary HCP. To achieve this, the Navigating MS steering committee recommends communication training coordinated by and through a patient advocacy group such as the MS Association of America or National MS Society. This training would affirm each HCP's unique role in the team and provide recommendations on how to effectively communicate between disciplines and how to successfully communicate benefit:risk from the discipline's perspective. In the future, it may be useful to have a tool that measures patient satisfaction with the communication with their healthcare team.

### Sharing best practice, existing tools and resources

Sharing existing tools promotes evidenced-based practice that prioritizes patient care and sets the standard of care globally. HCPs and advocacy groups have developed many useable resources and validated tools for facilitating improved communication and shared decision-making. However, it is apparent from discussion in the Navigating MS group that these are not being used widely and there is a lack of awareness around their existence and how to access them. In addition, some HCPs are developing their own patient checklists and questionnaires to use ahead of or within consultations. These practices illustrate a potential gap in the tools available and that there is an opportunity for shared approaches on a more global level.

One of the initial aims of Navigating MS is to collect and review existing tools and materials to agree which are valuable and create a mechanism to disseminate these for wider use, along with guidance on how and when to use them. The groups will also identify any gaps in the resources available and consider the development of new ones.

## Practical implementation

While huge advances have been made in our understanding and ability to treat MS, health outcomes in people in MS are still not as good as most would prefer. There are a number of contributors to this gap. First, discussions are sometimes predominantly focused on DMTs, minimizing discussions on symptom management and function. Further, it is well known that DMTs are incompletely effective, and we do not have biomarkers that biologically predict the safest, most effective therapy for a given individual. Beyond improving the science of MS, there are other factors that may play a role in outcomes: health and MS literacy, wellness, and complete engagement of the HCP and the person with MS in developing a treatment plan. These are topics that clinicians can address today to improve health outcomes in people with MS by engaging in a shared decision-making approach. Much of this involves behavior change to improve the dialogue between the HCP and the person with MS.

### Behavior change

Behavior change is always difficult, perhaps more so when it requires a change in the style of communication. Our hope is that MS HCPs will engage in comprehensive discussions with the individuals with MS to allow them to be active partners in the management of their disease. A common framework for this approach includes the concept of shared decision-making. Barriers to achieving this change in communication may include time constraints, interference of the EMR with both verbal and nonverbal communication, differences in opinion between the person with MS and their support partner, cultural differences, and external regulations limiting the treatment plan.

In addition, there may need to be behavior change from individuals with MS, some of whom may be used to relatively one-way communication from the HCP. Those who desire a more active role in their disease management may need coaching to effectively communicate their desires, values, and risk tolerances in a way that allows an effective therapeutic partnership.

### Moving forward

Navigating MS will be performing a survey to better understand barriers to optimal HCP–patient communication. Concurrent with this survey will be an effort to identify available tools to facilitate an enhanced communication strategy, which may range from an appropriate informational website on MS to an MS decision aid. After these efforts have been completed, gaps in the utility of these tools may be better identified and subsequently addressed.

To be a partner in the decision-making process, the individual with MS will need access to reliable information about the disease. Therefore, barriers to obtaining reliable information (and ways to overcome these hurdles) also need to be identified.

The Navigating MS group will remain engaged through the development of this position statement, the implementation of the barrier survey and the identification/development of aids for improving communication and the decision-making approach. This engagement will occur through telephone, web-based, and face-to-face meetings to maintain the excitement of the group that was ignited during the June 2016 meeting.

## Conclusions

There has been a remarkable evolution in the tools that allow clinicians to diagnosis and manage MS. However, the communication style between clinicians and people with MS in the changing landscape of MS therapeutics has not been as dynamic. Navigating MS believes that outcomes can be improved by transforming the individual with MS into an active partner in their healthcare management through a clearer understanding of their disease, more effective communication with the healthcare team, and a shared decision-making approach to treatment. To achieve this goal, the Navigating MS group will identify barriers to effective communication and develop strategies to improve communication with people with MS on a global level. The hope is that this change will improve health outcomes for all individuals living with MS.

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## References

1. Dilokthornsakul P, Valuck RJ, Nair KV, Corboy JR, Allen RR, Campbell JD. Multiple sclerosis prevalence in the United States commercially insured population. *Neurology* 2016;86:1014-21.
2. Atlas of MS. 2013. (Accessed 23 January 2017, at <https://www.msif.org/about-us/advocacy/atlas/>.)
3. Salter A, Thomas N, Tyry T, Cutter G, Marrie RA. Employment and absenteeism in working-age persons with multiple sclerosis. *J Med Econ* 2016:1-24.
4. Ma VY, Chan L, Carruthers KJ. Incidence, prevalence, costs, and impact on disability of common conditions requiring rehabilitation in the United States: stroke, spinal cord injury, traumatic brain injury, multiple sclerosis, osteoarthritis, rheumatoid arthritis, limb loss, and back pain. *Arch Phys Med Rehabil* 2014;95:986-95 e1.
5. Kobelt G, Thompson A, Berg J, et al. New insights into the burden and costs of multiple sclerosis in Europe. *Mult Scler* 2017:1352458517694432.
6. Giovannoni G, Butzkueven H, Dhib-Jalbut S, et al. Brain health: time matters in multiple sclerosis. *Mult Scler Relat Disord* 2016;9 Suppl 1:S5-S48.
7. Comi G, Filippi M, Barkhof F, et al. Effect of early interferon treatment on conversion to definite multiple sclerosis: a randomised study. *Lancet* 2001;357:1576-82.
8. Comi G, Martinelli V, Rodegher M, et al. Effect of glatiramer acetate on conversion to clinically definite multiple sclerosis in patients with clinically isolated syndrome (PreCISe study): a randomised, double-blind, placebo-controlled trial. *Lancet* 2009;374:1503-11.
9. Jacobs LD, Beck RW, Simon JH, et al. Intramuscular interferon beta-1a therapy initiated during a first demyelinating event in multiple sclerosis. CHAMPS Study Group. *N Engl J Med* 2000;343:898-904.
10. Kappos L, Edan G, Freedman MS, et al. The 11-year long-term follow-up study from the randomized BENEFIT CIS trial. *Neurology* 2016;87:978-87.
11. Kinkel RP, Kollman C, O'Connor P, et al. IM interferon beta-1a delays definite multiple sclerosis 5 years after a first demyelinating event. *Neurology* 2006;66:678-84.
12. Miller AE, Wolinsky JS, Kappos L, et al. Oral teriflunomide for patients with a first clinical episode suggestive of multiple sclerosis (TOPIC): a randomised, double-blind, placebo-controlled, phase 3 trial. *Lancet Neurol* 2014;13:977-86.
13. O'Connor P, Filippi M, Arnason B, et al. 250 microg or 500 microg interferon beta-1b versus 20 mg glatiramer acetate in relapsing-remitting multiple sclerosis: a prospective, randomised, multicentre study. *Lancet Neurol* 2009;8:889-97.
14. Goodin DS, Reder AT, Ebers GC, et al. Survival in MS: a randomized cohort study 21 years after the start of the pivotal IFNbeta-1b trial. *Neurology* 2012;78:1315-22.
15. Goodin DS, Ebers GC, Cutter G, et al. Cause of death in MS: long-term follow-up of a randomised cohort, 21 years after the start of the pivotal IFNbeta-1b study. *BMJ Open* 2012;2.
16. Clanet MC, Wolinsky JS, Ashton RJ, Hartung HP, Reingold SC. Risk evaluation and monitoring in multiple sclerosis therapeutics. *Mult Scler* 2014;20:1306-11.
17. Reen GK, Silber E, Langdon DW. Interventions to support risk and benefit understanding of disease-modifying drugs in Multiple Sclerosis patients: A systematic review. *Patient Educ Couns* 2017;100:1031-48.

18. Reen GK, Silber E, Langdon DW. Multiple sclerosis patients' understanding and preferences for risks and benefits of disease-modifying drugs: A systematic review. *J Neurol Sci* 2017;375:107-22.
19. La Mantia L, Eoli M, Salmaggi A, Milanese C. Does a placebo-effect exist in clinical trials on multiple sclerosis? Review of the literature. *Ital J Neurol Sci* 1996;17:135-9.
20. Consortium of Multiple Sclerosis Centers. Comprehensive care in multiple sclerosis. Hackensack, NJ: Consortium of Multiple Sclerosis Centers; 2010 (Accessed February 2017, at [http://c.ymcdn.com/sites/www.mscares.org/resource/collection/4CB3E940-0D5C-4ADD-9C48-8FA7AAAC2DB9/CMSC\\_WhitePaper\\_Comprehensive\\_Care\\_in\\_MS.pdf](http://c.ymcdn.com/sites/www.mscares.org/resource/collection/4CB3E940-0D5C-4ADD-9C48-8FA7AAAC2DB9/CMSC_WhitePaper_Comprehensive_Care_in_MS.pdf).)
21. Nancarrow SA, Booth A, Ariss S, Smith T, Enderby P, Roots A. Ten principles of good interdisciplinary team work. *Hum Resour Health* 2013;11:19.
22. Sackett DL, Rosenberg WM, Gray JA, Haynes RB, Richardson WS. Evidence based medicine: what it is and what it isn't. *BMJ* 1996;312:71-2.
23. Vellinga MM, Castelijns JA, Barkhof F, Uitdehaag BM, Polman CH. Postwithdrawal rebound increase in T2 lesional activity in natalizumab-treated MS patients. *Neurology* 2008;70:1150-1.
24. Kerbrat A, Le Page E, Leray E, et al. Natalizumab and drug holiday in clinical practice: an observational study in very active relapsing remitting multiple sclerosis patients. *J Neurol Sci* 2011;308:98-102.
25. Havla JB, Pellkofer HL, Meinl I, Gerdes LA, Hohlfeld R, Kumpfel T. Rebound of disease activity after withdrawal of fingolimod (FTY720) treatment. *Arch Neurol* 2012;69:262-4.
26. Barry MJ, Edgman-Levitan S. Shared decision making--pinnacle of patient-centered care. *N Engl J Med* 2012;366:780-1.
27. Tintore M, Alexander M, Costello K, et al. The state of multiple sclerosis: current insight into the patient/health care provider relationship, treatment challenges, and satisfaction. *Patient Prefer Adherence* 2017;11:33-45.
28. Skovgaard L, Nicolajsen PH, Pedersen E, et al. Use of complementary and alternative medicine among people with multiple sclerosis in the Nordic countries. *Autoimmune Dis* 2012;2012:841085.
29. Coulter A, Collins A. Making shared-decision-making a reality. No decision about me, without me. London The Kings Fund; 2011 (Accessed February 2017, at [https://www.kingsfund.org.uk/sites/files/kf/Making-shared-decision-making-a-reality-paper-Angela-Coulter-Alf-Collins-July-2011\\_0.pdf](https://www.kingsfund.org.uk/sites/files/kf/Making-shared-decision-making-a-reality-paper-Angela-Coulter-Alf-Collins-July-2011_0.pdf).)
30. Elwyn G, Laitner S, Coulter A, Walker E, Watson P, Thomson R. Implementing shared decision making in the NHS. *BMJ* 2010;341:c5146.
31. Bell RA, Kravitz RL, Thom D, Krupat E, Azari R. Unmet expectations for care and the patient-physician relationship. *J Gen Intern Med* 2002;17:817-24.
32. Street RL, Jr., Makoul G, Arora NK, Epstein RM. How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Educ Couns* 2009;74:295-301.
33. Legare F, Thompson-Leduc P. Twelve myths about shared decision making. *Patient Educ Couns* 2014;96:281-6.
34. Heesen C, Solari A, Giordano A, Kasper J, Kopke S. Decisions on multiple sclerosis immunotherapy: new treatment complexities urge patient engagement. *J Neurol Sci* 2011;306:192-7.
35. Rieckmann P, Boyko A, Centonze D, et al. Achieving patient engagement in multiple sclerosis: A perspective from the multiple sclerosis in the 21st Century Steering Group. *Mult Scler Relat Disord* 2015;4:202-18.

36. von Puckler A. A patient's perspective of partnership in the treatment of multiple sclerosis: MS regimes-an orchestrated approach. *J Neurol Sci* 2013;335:1-4.
37. Wilson L, Loucks A, Bui C, et al. Patient centered decision making: use of conjoint analysis to determine risk-benefit trade-offs for preference sensitive treatment choices. *J Neurol Sci* 2014;344:80-7.
38. Chakraborty S, Boudier F. The future of risk communication and the role of the pharmaceutical industry. *Curr Drug Saf* 2013;8:4-10.
39. Johnson FR, Van Houtven G, Ozdemir S, et al. Multiple sclerosis patients' benefit-risk preferences: serious adverse event risks versus treatment efficacy. *J Neurol* 2009;256:554-62.
40. Tur C, Tintore M, Vidal-Jordana A, et al. Risk acceptance in multiple sclerosis patients on natalizumab treatment. *PLoS One* 2013;8:e82796.
41. Lynd LD, Traboulee A, Marra CA, et al. Quantitative analysis of multiple sclerosis patients' preferences for drug treatment: a best-worst scaling study. *Ther Adv Neurol Disord* 2016;9:287-96.
42. Center for Advancing Health. A new definition of patient engagement: what is engagement and why is it important? Washington, DC: Center for Advancing Health; 2010 (Accessed February 2017, at [http://www.cfah.org/file/CFAH\\_Engagement\\_Behavior\\_Framework\\_current.pdf](http://www.cfah.org/file/CFAH_Engagement_Behavior_Framework_current.pdf).)
43. Coulter A. Patient engagement--what works? *J Ambul Care Manage* 2012;35:80-9.
44. Kopke S, Kasper J, Muhlhauser I, Nubling M, Heesen C. Patient education program to enhance decision autonomy in multiple sclerosis relapse management: a randomized-controlled trial. *Mult Scler* 2009;15:96-104.
45. Kopke S, Kern S, Ziemssen T, et al. Evidence-based patient information programme in early multiple sclerosis: a randomised controlled trial. *J Neurol Neurosurg Psychiatry* 2014;85:411-8.
46. Solari A, Martinelli V, Trojano M, et al. An information aid for newly diagnosed multiple sclerosis patients improves disease knowledge and satisfaction with care. *Mult Scler* 2010;16:1393-405.
47. Hay MC, Strathmann C, Lieber E, Wick K, Giesser B. Why patients go online: multiple sclerosis, the internet, and physician-patient communication. *Neurologist* 2008;14:374-81.
48. Popovic K, Smith C, Hellebusch SJ. Attitudes on the use of social media in healthcare communications. *J Comm Healthcare* 2013;6:22-8.
49. Bruce J, Bruce A, Lynch S, et al. A pilot study to improve adherence among MS patients who discontinue treatment against medical advice. *J Behav Med* 2016;39:276-87.
50. Smith DC, Lanesskog D, Cleeland L, Motl R, Weikert M, Dlugonski D. Motivational interviewing may improve exercise experience for people with multiple sclerosis: A small randomized trial. *Health Soc Work* 2012;37:99-109.
51. Miller WR, Rollnick S. *Motivational interviewing: helping people change*. 3rd ed. New York, NY: Guilford Press; 2013.
52. Kachuck NJ. When neurologist and patient disagree on reasonable risk: new challenges in prescribing for patients with multiple sclerosis. *Neuropsychiatr Dis Treat* 2011;7:197-208.
53. Cocksedge S, George B, Renwick S, Chew-Graham CA. Touch in primary care consultations: qualitative investigation of doctors' and patients' perceptions. *Br J Gen Pract* 2013;63:e283-90.
54. Haase R, Schultheiss T, Kempcke R, Thomas K, Ziemssen T. Use and acceptance of electronic communication by patients with multiple sclerosis: a multicenter questionnaire study. *J Med Internet Res* 2012;14:e135.



55. Cass SJ, Ball LE, Leveritt MD. Passive interventions in primary healthcare waiting rooms are effective in promoting healthy lifestyle behaviours: an integrative review. *Aust J Prim Health* 2016;22:198-210.
56. Marcinowicz L, Konstantynowicz J, Godlewski C. Patients' perceptions of GP non-verbal communication: a qualitative study. *Br J Gen Pract* 2010;60:83-7.
57. Makoul G, Curry RH, Tang PC. The use of electronic medical records: communication patterns in outpatient encounters. *J Am Med Inform Assoc* 2001;8:610-5.
58. Tams R, Prangnell SJ, Daisley A. Helping families thrive in the face of uncertainty: Strengths based approaches to working with families affected by progressive neurological illness. *NeuroRehabilitation* 2016;38:257-70.
59. Jessup RL. Interdisciplinary versus multidisciplinary care teams: do we understand the difference? *Aust Health Rev* 2007;31:330-1.
60. Kuziemyky CE, Borycki EM, Purkis ME, et al. An interdisciplinary team communication framework and its application to healthcare 'e-teams' systems design. *BMC Med Inform Decis Mak* 2009;9:43.

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