

# MS in the 21<sup>st</sup> Century

## Unmet needs survey

### HCP SURVEY QUESTIONS

#### **Q1: What are the biggest challenges for healthcare professionals when diagnosing MS?**

(Please choose one or more options)

- Not enough time with the patient
- Explaining disease progression
- Lack of good quality patient materials
- Introducing treatment options
- Explaining treatment risks
- Providing emotional support
- I do not have any challenges

#### **Q2: Do you talk about disease progression with your patients?**

(Please select all that apply)

- I always discuss disease progression with my patients
- I sometimes discuss disease progression with my patients
- Patients do not want to talk about disease progression
- I do not discuss disease progression with my patients

#### **Q3: Which of these are useful for disease progression discussions with your patients?**

(Please indicate the level of usefulness of each option)

- |  | Not useful | Useful | Very useful |
|--|------------|--------|-------------|
| - Scientific graphs and images                 |            |        |             |
| - Analogies relevant to the patient            |            |        |             |
| - Written information                          |            |        |             |
| - Allowing the patient to guide the discussion |            |        |             |
| - Online resources                             |            |        |             |

#### **Q4: Why might discussions about disease progression with your patients not take place?**

(Please choose one or more options)

- Patients do not understand the concept of disease progression
- Patients do not want to think about disease progression
- Lack of time during appointments
- Patients expect HCPs to raise the topic, if relevant
- Talking about disease progression is too upsetting for patients
- Patients may not feel empowered to discuss disease progression
- There is nothing I can do about disease progression; why talk about it?

**Q5: To what extent are your patients involved in treatment decisions?**

Not involved    Somewhat involved    Fully involved

- Patient involvement

**Q6: How satisfied are your patients with their level of involvement in treatment decisions?**

Very dissatisfied    Dissatisfied    Moderately dissatisfied    Satisfied    Very satisfied

- Patient satisfaction

**Q7: What do you feel is most important to patients when making treatment decisions?**

(Please choose one or more options)

- Simplicity of treatment
- How the treatment is administered
- Risks of treatment
- Side effects
- Treatment that slows disease progression
- Practical considerations\*  
\*Need for someone to administer, monitoring requirements, cost and affordability, family planning etc.

**Q8: What forms of information are useful to patients when making treatment decisions?**

(Please indicate the level of usefulness of each option)

Not useful                      Useful                      Very useful

- Clinical data and scientific evidence
- Graphs and images
- Analogies relevant to the patient
- Written resources
- Online resources
- Independent patient research

**Q9: What are the biggest barriers to effective communication between healthcare professionals and patients?**

(Please choose one or more options)

- Insufficient patient knowledge of MS
- Misunderstanding of patient priorities
- Difficulty explaining complicated information to patients
- Lack of educational resources
- Lack of time with doctor
- I do not feel there is an issue

**Q10: How beneficial would the following resources be in overcoming the communication barriers between patients and healthcare professionals?**

(Please indicate the level of benefit for each option)

Not beneficial                      Beneficial                      Very beneficial

- Joint educational programmes
- HCP and patient communication tools
- Written materials
- Online resources

**Q11: What additional support is currently available for patients in your practice?**

(Please select all that apply)

- MS nurse
- Social/psychological support
- Information about employment
- Information about practical implications of a diagnosis  
e.g. insurance and driving licence
- Support for family and/or carers
- Written information about MS
- Other
- None of the above

**PATIENT SURVEY QUESTIONS**

**Q1: When you were diagnosed with MS, which of the following did you find most challenging?**

(Please choose one or more options)

- Not enough time with the doctor
- Understanding disease progression
- Lack of good quality patient materials
- Understanding my treatment options
- Understanding treatment risks
- Finding emotional support
- I did not have any challenges

**Q2: Do you talk about disease progression with your doctor?**

(Please select all that apply)

- I always discuss disease progression with my doctor
- I sometimes discuss disease progression with my doctor
- I do not want to talk about disease progression
- I have not discuss disease progression with my doctor

**Q3: Which of these are useful for disease progression discussions with your doctor?**

(Please indicate the level of usefulness of each option)

- |  | Not useful | Useful | Very useful |
|--|------------|--------|-------------|
| - Scientific graphs and images                 |            |        |             |
| - Analogies relevant to the patient            |            |        |             |
| - Written information                          |            |        |             |
| - Allowing the patient to guide the discussion |            |        |             |
| - Online resources                             |            |        |             |

**Q4: Why might discussions about disease progression with your doctor not take place?**

(Please choose one or more options)

- I do not understand the concept of disease progression
- I do not want to think about disease progression
- Lack of time during appointments
- I expect my doctor to raise the topic, if relevant
- Talking about disease progression is too upsetting
- I do not feel empowered to discuss disease progression
- There is nothing I can do about disease progression; why talk about it?

**Q5: To what extent are you involved in treatment decisions?**

Not involved    Somewhat involved    Fully involved

- Involvement

**Q6: How satisfied are you with the level of involvement you have in treatment decisions?**

Very dissatisfied    Dissatisfied    Moderately dissatisfied    Satisfied    Very satisfied

- Satisfaction

**Q7: What do you feel is most important to you when making treatment decisions?**

(Please choose one or more options)

- Simplicity of treatment
- How the treatment is administered
- Risks of treatment
- Side effects
- Treatment that slows disease progression
- Practical considerations\*  
\*Need for someone to administer, monitoring requirements, cost and affordability, family planning etc.

**Q8: What forms of information do you find most useful when making treatment decisions?**

(Please indicate the level of usefulness of each option)

Not useful                      Useful                      Very useful

- Clinical data and scientific evidence
- Graphs and images
- Analogies relevant to me
- Written resources
- Online resources
- Independent research

**Q9: What are the biggest barriers to effective communication between doctors and patients?**

(Please choose one or more options)

- Insufficient patient knowledge of MS
- Doctors misunderstand patient priorities
- Difficulty understanding complicated information
- Lack of educational resources
- Lack of time with doctor
- I do not feel there is an issue

**Q10: How beneficial would the following resources be in overcoming the communication barriers between patients and doctors?**

(Please indicate the level of benefit for each option)

- |  | Not beneficial | Beneficial | Very beneficial |
|--|----------------|------------|-----------------|
| - Joint educational programmes           |                |            |                 |
| - Doctor and patient communication tools |                |            |                 |
| - Written materials                      |                |            |                 |
| - Online resources                       |                |            |                 |

**Q11: What additional support is currently available for patients in your clinic?**

(Please select all that apply)

- MS nurse
- Social/psychological support
- Information about employment
- Information about practical implications of a diagnosis  
e.g. insurance and driving licence
- Support for family and/or carers
- Written information about MS
- Other
- None of the above