Supplementary Material

Guiding multiple sclerosis care: an update to the 2013 consensus statement from the MS in the 21st Century Steering Group

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Online Resource S1: core panel contributors and their affiliations

Core panel attending meeting 1, 2, and 3: Raed Alroughani (Neurologist, Salmiya, Kuwait); Elisabeth G. Celius (Neurologist, Oslo, Norway); Paola Kruger (person living with multiple sclerosis (PwMS)/patient advocacy group (PAG) representative of European Patients' Academy on Therapeutic Innovation [EUPATI], Rome, Italy); Celia Oreja-Guevara (Neurologist, Madrid, Spain); Amber Plant (PAG, Shift.MS, Leeds, UK); Maija Pontaga (PwMS/PAG, Latvian Multiple Sclerosis Association, Riga, Latvia); Peter Rieckmann (Neurologist, Bischofswiesen, Germany); and Marja-Liisa Sumelahti (Neurologist, Tampere, Finland). All core panel members were existing contributors to the MS in the 21st Century (MS21) initiative, with the exception of Amber Plant, who represented Shift.MS, an organisation that has regularly contributed to the initiative.

Three further PAG representatives joined the core panel for meeting 2 and 3: Amanda Montague (Multiple Sclerosis Association of America, New York, NY, USA, and MS21 member); Elisabeth Kasilingam (European Multiple Sclerosis Platform, Brussels, Belgium, and MS21 member); and Kaye Gooch/Leslie Ritter (National Multiple Sclerosis Society, Washington DC, USA [shared role]).

Online Resource S2: statements shared at first round of voting

MS care: Delphi consensus – voting round 1

Survey questions (SurveyMonkey)

Before reviewing the statements, please answer the following questions about yourself. These will be kept anonymous and will be used to report on the demographic of our survey respondents and to highlight any trends that may arise in analysis.

1. I am a…
    a. Person living with MS
    b. Healthcare professional
    c. Patient organisation representative/patient advocate
    d. Other (please specify) ___

2. What is your age bracket?
    a. 18–25 years old
    b. 26–34 years old
    c. 35–50 years old
    d. 50–65 years old
    e. Over 65 years old

3. What is your country of residence?

[Open text box]

4. PwMS only – How long ago were you diagnosed with MS?
    a. Within the last 12 months
    b. 1–2 years
    c. 3–5 years
    d. 6–10 years
    e. Over 10 years
    f. Not applicable – I'm not a person living with MS

5. HCPs only – How long have you been working in MS?
    a. Less than 12 months
    b. 1–2 years
    c. 3–5 years
    d. 6–10 years
    e. Over 10 years
    f. Not applicable – I'm not an HCP

The questions that will follow are grouped into three themes, each covered in a separate section:

1. **Optimising current MS care provision**
2. **Facilitating shared decision making and patient education**
3. **Continuing MS research and development**

Please use the sliding scale to let us know the extent to which you agree with the statement, and the comment box to provide any feedback on the statement or amendments you feel should be made.

If you have any issues or need clarification, please contact us by email (CommsIS-MS21@lumanity.com).

Optimising current MS care provision

Please state to what extent you agree with the following statements. Please consider each statement independently of other statements.

Access to quick and decisive treatment after diagnosis

Healthcare professionals are advised to treat MS as soon as possible and without delay.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Healthcare professionals are advised to work with the PwMS to agree on an effective personalised treatment plan that addresses relapses, relapse associated worsening of disease, and progression independent of relapse activity, as appropriate.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Healthcare professionals are advised to provide PwMS with a general overview of how MS can develop, balancing the positive and negative aspects, and signposting PwMS to lay friendly material through patient advocacy groups, for example, to support their understanding of MS.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Healthcare professionals are advised to prioritise listening to and understanding PwMS in order to understand their individual needs (e.g., personal/social life and employment status) and personalise their treatment. Consultation framework tools can help structure appointments to address all aspects.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Needs at diagnosis

Healthcare professionals are advised to sensitively provide the option for patients to come to the diagnosis consultation accompanied by someone and ask the patient if they want the person to be present during the consultation.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Healthcare professionals are advised to give PwMS the option to record the conversation, so that they can take time to process the information after the consultation, and provide details of a healthcare professional they can speak to for follow-up questions.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Healthcare professionals are advised to provide practical advice outlining actions that PwMS may need to take following their diagnosis (e.g., notifying driving licence agency, registering for utilities discount schemes, health insurance, etc.) or to signpost PwMS to available resources.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Healthcare professionals are advised to inform PwMS about MS patient organisations and patient-friendly resources as reliable sources of information and support. Healthcare professionals are advised to follow-up shortly after to ensure that PwMS have all the information and support they need.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Healthcare professionals and MS care teams are advised to aim to build a professional relationship and shared history with PwMS over time.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Healthcare and pharmaceutical organisations are advised to improve healthcare professional training on communication skills, including patient-friendly language and managing the challenges of sharing MS diagnoses.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

For complex diagnoses, healthcare professionals are advised to consider referral to an MS centre for diagnosis and treatment.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Access to multifunctional care

Health organisations, payors and associated stakeholders are advised to provide PwMS early access to rehabilitation services (physiotherapy/occupational therapy) and psychological services.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Integration of services in the multifunctional healthcare team

Healthcare organisations are advised to facilitate and encourage open and well-integrated multidisciplinary healthcare in MS clinics.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Healthcare professionals are advised to work on optimising multi-disciplinary working through open communication and involving the right practitioners at the right time.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Better utilisation of technology to support virtual care, communication and data collection

Healthcare professionals are advised to utilise hybrid care technology such as telemedicine and apps (where the PwMS is comfortable using these) to continuously monitor health information and tailor treatment to the individual needs of each person living with MS.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Healthcare organisations and associated stakeholders are advised to educate PwMS and healthcare professionals on how to make the most out of technology for data collection (e.g., apps, remote healthcare platforms) to support better care.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Hospitals and health institutions are advised to develop accessible technology that can be used by HCPs and PwMS, to aid individualised care.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Individualised care

It is paramount that healthcare professionals aim to implement individualised care not solely through medical treatment, but through a holistic approach, including lifestyle changes. Utilisation of self-care plans should be considered and followed-up on regularly by the healthcare professional. [Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Healthcare professionals are advised to provide PwMS with support to make lifestyle changes, such as quitting smoking, in order to promote long-term health and reduce comorbidities. The support provided should include strategies to successfully implement changes and referral to specialists who can provide additional assistance.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Considerations for ageing populations

Healthcare organisations and associated stakeholders are advised to provide more resources and support needed to manage MS in an ageing population

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Healthcare professionals are advised to recognise the specific needs of ageing PwMS, particularly with regard to adopting new technologies and eligibility for treatments, and provide support and resources with regular follow-up, as appropriate.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Healthcare professionals are advised to help PwMS discuss symptoms they may be experiencing with their HCP, even in the absence of relapses or MRI activity, and to be vigilant towards possible MS symptoms that could be disguised as effects of ageing.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Facilitating shared decision making and patient education

Please state to what extent you agree with the following statements. Please consider each statement independently of other statements.

Patient involvement in care

Healthcare organisations and associated stakeholders are advised to provide PwMS with the educational resources that can equip them to use MS vocabulary and discuss MS-related decisions with confidence.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Patient advocacy groups and HCPs are advised to encourage PwMS to be more engaged with their care and treatment. Providing PwMS with balanced information and support can empower them to take part in shared decision making.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Healthcare professionals are advised to offer information about MS to carers and/or parents if the PwMS desires their input in their care.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

PwMS are advised to discuss symptoms they may be experiencing with their HCP, even in the absence of relapses or MRI activity.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Accessibility of educational resources

Pharmaceutical organisations, patient advocacy groups and other stakeholders are advised to create resources that bridge the language gap between researchers and PwMS.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Pharmaceutical organisations, patient advocacy groups and associated stakeholders are advised to create plain language summary publications to help summarise important research in a way that is relevant to PwMS.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Pharmaceutical organisations, patient advocacy groups and associated stakeholders are advised to work with patient organisations to create more multimedia resources, e.g., videos, and share them through a variety of channels such as social media to better address how PwMS consume information.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Healthcare organisations and patient advocacy groups are advised to ensure that where materials are discussing potential treatments, it is made clear these may not be available to PwMS immediately.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Pharmaceutical and healthcare organisations are advised to provide healthcare professionals with a larger variety of educational resources, to enable healthcare professionals to provide tailored education.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Continuing MS research and development

The following statements are draft recommendations from the Delphi panel for relevant parties, in order to achieve life with MS without the burden of symptoms. Please state to what extent you agree with the following statements. Please consider each statement independently of other statements.

Developing treatment options to manage invisible symptoms

Healthcare professionals are advised to discuss and develop effective treatment management plans to minimise the impact of invisible symptoms.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Healthcare professionals are advised to tailor their care to be specific to the symptoms experienced by the individual person living with MS, and not underestimate the impact any symptom can have on their quality of life.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Developing treatment options for people whose MS is progressing

All stakeholders, including pharmaceutical organisations, are advised to prioritise research and development of treatments for unmet needs, such as progressive MS and progression independent of relapse activity (PIRA).

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Healthcare professionals and healthcare organisations and institutions are advised to provide more support (physical, emotional and psychological) to people whose MS is progressing.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Developing treatment options for remyelination and reversing damage

All stakeholders, including pharmaceutical organisations, are advised to conduct more research to develop treatment options for remyelination and the reversal of damage caused by MS.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Preventing MS

Pharmaceutical organisations are advised to conduct more research to determine factors that are preventive in MS (for example, the potential role of Epstein-Barr virus in causing MS).

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Involvement of PwMS in research and development

PwMS are advised to be considered research partners, not just participants, and they should be informed about the outcomes of the research.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

PwMS are advised to be involved in decisions about what research takes place and every following stage, and consulted if changes are planned.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Patient-reported outcomes should be focused and targeted and considered as important clinical endpoints, especially when considering the tolerability of a treatment based on side effects.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Patient education should be a priority to ensure informed consent for study participation.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

PwMS who participate in the research should be representative of other PwMS and reflective of the diverse MS population.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Surveys and questionnaires should be tailored to PwMS so that they are easy to understand and complete in order to develop patient-reported outcomes.

[Sliding scale: 1 – Strongly disagree, 2 – Disagree, 3 – Neutral, 4 – Agree, 5 – Strongly agree]

Feedback:

[open text box]

Thank you for taking the time to complete this questionnaire.

We will be in touch to seek your views about the refined statements in another survey. In the meantime, if you have any questions about your participation in this survey, please contact CommsIS-MS21@lumanity.com.

Online Resource S3: Statements shared at second round of voting

MS care: Delphi consensus – voting round 2

Survey questions (SurveyMonkey)

Before we begin, please answer the following questions about yourself. These will be kept anonymous and will be used to report on the demographic of our survey respondents and to highlight any trends that may arise in analysis.

6. I am a…
    a. Person living with MS
    b. Healthcare professional
    c. Patient organisation representative/patient advocate
    d. Other (please specify) ___

7. What is your age bracket?
    f. 18–25 years old
    g. 26–34 years old
    h. 35–50 years old
    i. 50–65 years old
    j. Over 65 years old

8. What is your country of residence?

[Open text box]

9. People living with MS only – How long ago were you diagnosed with MS?
    g. Within the last 12 months
    h. 1–2 years
    i. 3–5 years
    j. 6–10 years
    k. Over 10 years
    l. Not applicable – I'm not a person living with MS

10. Healthcare professionals only – How long have you been working in MS?
    g. Less than 12 months
    h. 1–2 years
    i. 3–5 years
    j. 6–10 years
    k. Over 10 years
    l. Not applicable – I'm not an HCP

Task 1. There are many different aspects to MS care - but which ones are most important to focus on, to improve outcomes for people with MS? Please rank the following topics in order of importance, where 1 is the top priority and 14 is the least priority:

a) **Developing treatment options to manage invisible symptoms**
b) **Access to multifunctional care (things like rehabilitation and psychological support)**
c) **Developing treatment options for people whose MS is progressing**
d) **Preventing MS**
e) **Patient involvement in care**
f) **Accessibility of educational resources**
g) **Ensuring people living with MS are involved in research and development**
h) **Access to quick and decisive treatment after diagnosis**
i) **Considerations for ageing people**
j) **Developing treatment options for remyelination and reversing damage**
k) **Addressing the needs of patients at the time of diagnosis**
l) **Ensuring all care services work effectively together**
m) **Better use of technology to support virtual care, communication, and data collection**
n) **Individualised care**

Task 2. Approving the refined statements

You've seen these statements before, but we've refined them based on what you've told us. Please would you let us know if you're now happy with them?

Please let us know if you now agree with the statement, or use the comment box to provide any amendments you feel should be made.

If you have any issues or need clarification, please contact us by email (CommsIS-MS21@lumanity.com).

Continuing MS research and development

Developing treatment options to manage invisible symptoms

Healthcare professionals are advised to discuss and develop effective treatment management plans to minimise the impact of invisible symptoms.

Agree

Disagree, because:

[open text box]

Healthcare professionals are advised to tailor their care to be specific to the symptoms experienced by the individual person living with MS, and not underestimate the impact any symptom can have on their quality of life.

Agree

Disagree, because:

[open text box]

Developing treatment options for people whose MS is progressing

All stakeholders, including pharmaceutical organisations, are advised to prioritise research and development of treatments for unmet needs, such as progressive MS and progression independent of relapse activity (PIRA).

Agree

Disagree, because:

[open text box]

Healthcare professionals and healthcare organisations and institutions are advised to provide more support (physical, emotional and psychological) to people whose MS is progressing.

Agree

Disagree, because:

[open text box]

Developing treatment options for remyelination and reversing damage

All stakeholders, including pharmaceutical organisations, are advised to conduct more research to develop treatment options for remyelination and the reversal of damage caused by MS.

Agree

Disagree, because:

[open text box]

Preventing MS

Pharmaceutical organisations are advised to conduct more research to determine factors that are preventive in MS (for example, the potential role of Epstein-Barr virus in causing MS).

Agree

Disagree, because:

[open text box]

Involvement of PwMS in research and development

PwMS are advised to be considered research partners, not just participants, and they should be informed about the outcomes of the research.

Agree

Disagree, because:

[open text box]

PwMS are advised to be involved in decisions about what research takes place and every following stage, and consulted if changes are planned.

Agree

Disagree, because:

[open text box]

Patient-reported outcomes should be focused and targeted and considered as important clinical endpoints, especially when considering the tolerability of a treatment based on side effects.

Agree

Disagree, because:

[open text box]

Patient education should be a priority to ensure informed consent for study participation.

Agree

Disagree, because:

[open text box]

PwMS who participate in the research should be representative of other PwMS and reflective of the diverse MS population.

Agree

Disagree, because:

[open text box]

Surveys and questionnaires should be tailored to PwMS so that they are easy to understand and complete in order to develop patient-reported outcomes.

Agree

Disagree, because:

[open text box]

Facilitating shared decision making and patient education

Patient involvement in care

Healthcare organisations and associated stakeholders are advised to provide PwMS with the educational resources that can equip them to use MS vocabulary and discuss MS-related decisions with confidence.

Agree

Disagree, because:

[open text box]

Patient advocacy groups and HCPs are advised to encourage PwMS to be more engaged with their care and treatment. Providing PwMS with balanced information and support can empower them to take part in shared decision making.

Agree

Disagree, because:

[open text box]

Healthcare professionals are advised to offer appropriate-level information about MS to carers and/or parents if the patient desires their input in their care.

Agree

Disagree, because:

[open text box]

Patients are advised to discuss symptoms they may be experiencing with their HCP, even in the absence of relapses or MRI activity.

Agree

Disagree, because:

[open text box]

Accessibility of educational resources

Pharmaceutical organisations, patient advocacy groups and other stakeholders are advised to create resources that bridge the language gap between researchers and PwMS.

Agree

Disagree, because:

[open text box]

Pharmaceutical organisations, patient advocacy groups and associated stakeholders are advised to create plain language summary publications to help summarise important research in a way that is relevant to PwMS.

Agree

Disagree, because:

[open text box]

Pharmaceutical organisations, patient advocacy groups and associated stakeholders are advised to work with patient organisations to create more multimedia resources, e.g., videos, and share them through a variety of channels such as social media to better address how PwMS consume information.

Agree

Disagree, because:

[open text box]

Healthcare organisations and patient advocacy groups are advised to ensure that where materials are discussing potential treatments, it is made clear these may not be available to PwMS immediately.

Agree

Disagree, because:

[open text box]

Pharmaceutical and healthcare organisations are advised to provide healthcare professionals with a larger variety of educational resources, to enable healthcare professionals to provide tailored education.

Agree

Disagree, because:

[open text box]

Optimising current MS care provision

Access to quick and decisive treatment after diagnosis

Healthcare professionals are advised to treat MS as soon as possible and without delay.

Agree

Disagree, because:

[open text box]

Healthcare professionals are advised to work with the PwMS to agree on an effective personalised treatment plan that addresses relapses, relapse associated worsening of disease, and progression independent of relapse activity, as appropriate.

Agree

Disagree, because:

[open text box]

Healthcare professionals are advised to provide PwMS with a general overview of how MS can develop, balancing the positive and negative aspects, and signposting PwMS to lay friendly material through patient advocacy groups, for example, to support their understanding of MS.

Agree

Disagree, because:

[open text box]

Healthcare professionals are advised to prioritise listening to and understanding PwMS in order to understand their individual needs (e.g., personal/social life and employment status) and personalise their treatment. Consultation framework tools can help structure appointments to address all aspects.

Agree

Disagree, because:

[open text box]

Needs at diagnosis

Healthcare professionals are advised to sensitively provide the option for patients to come to the diagnosis consultation accompanied by someone and ask the patient if they want the person to be present during the consultation.

Agree

Disagree, because:

[open text box]

The option to record the consultation should be provided, so that PwMS can take time to process the information outside of the clinic. Details of a healthcare professional they can speak to for follow-up questions should also be given.

Agree

Disagree, because:

[open text box]

Healthcare professionals are advised to signpost PwMS to available resources and, where possible, provide practical advice outlining actions that PwMS may need to take following their diagnosis, such as advising who they might need to notify.

Agree

Disagree, because:

[open text box]

Healthcare professionals are advised to inform patients about MS patient organisations and patient-friendly resources as reliable sources of information and support. Healthcare professionals are advised to follow-up to ensure that PwMS have all the information and support they need.

Agree

Disagree, because:

[open text box]

Healthcare professionals and MS care teams are advised to aim to build a professional relationship and shared history with PwMS over time.

Agree

Disagree, because:

[open text box]

Healthcare and pharmaceutical organisations are advised to improve healthcare professional training on communication skills, including patient-friendly language and managing the challenges of sharing MS diagnoses.

Agree

Disagree, because:

[open text box]

For complex diagnoses, healthcare professionals are advised to consider referral to an MS centre for diagnosis and treatment

Agree

Disagree, because:

[open text box]

Access to multifunctional care

Health organisations, payors and associated stakeholders are advised to provide PwMS early access to rehabilitation services (physiotherapy/occupational therapy) and psychological services.

Agree

Disagree, because:

[open text box]

Integration of services in the multifunctional healthcare team

Healthcare organisations are advised to facilitate and encourage open and well-integrated multi-disciplinary healthcare in MS clinics.

Agree

Disagree, because:

[open text box]

Healthcare professionals are advised to work on optimising multi-disciplinary working through open communication and involving the right practitioners at the right time.

Agree

Disagree, because:

[open text box]

Better utilisation of technology to support virtual care, communication and data collection

Healthcare professionals are advised to supplement care, where possible, with innovative care technology such as telemedicine and apps (where the PwMS is comfortable using these) to continuously monitor health information and tailor treatment to the individual needs of each person living with MS.

Agree

Disagree, because:

[open text box]

Healthcare organisations and associated stakeholders are advised to offer to educate PwMS and healthcare professionals on how to make the most out of technology for data collection (e.g., apps, remote healthcare platforms) to support better care where available.

Agree

Disagree, because:

[open text box]

Hospitals and health institutions are advised to co-design with patients accessible technology that can be used to aid individualised care.

Agree

Disagree, because:

[open text box]

Individualised care

It is paramount that healthcare professionals aim to implement individualised care not solely through medical treatment, but through a holistic approach, including lifestyle changes. Utilisation of self-care plans should be considered and followed-up on regularly by the healthcare professional.

Agree

Disagree, because:

[open text box]

Healthcare professionals are advised to provide patients with support to make lifestyle changes, such as quitting smoking, in order to promote long-term health and reduce comorbidities. The support provided should include strategies to successfully implement changes and referral to specialists who can provide additional assistance.

Agree

Disagree, because:

[open text box]

Considerations for ageing populations

Healthcare organisations and associated stakeholders are advised to provide more resources and support needed to manage MS in an ageing population.

Agree

Disagree, because:

[open text box]

Healthcare professionals are advised to recognise the specific needs of ageing PwMS, particularly with regard to adopting new technologies and eligibility for treatments, and provide support and resources with regular follow-up, as appropriate.

Agree

Disagree, because:

[open text box]

Healthcare professionals are advised to help PwMS discuss symptoms they may be experiencing with their HCP, even in the absence of relapses or MRI activity, and to be vigilant towards possible MS symptoms that could be disguised as effects of ageing.

Agree

Disagree, because:

[open text box]

Thank you so much for taking the time to complete this questionnaire.

Your views are so valuable to the success of this project. We hope to publish the results in a medical journal. if you have any questions about your participation in this survey, please contact CommsIS-MS21@lumanity.com.