

MSIF Essential Medicines Panel (MEMP)

Guidelines for essential disease-modifying therapies for multiple sclerosis for low-resource settings

Public comment

Before publication of the guidelines, the recommendations were open for public comment on MSIF's website from the 12th of January until 27th of January 2023.

We received a total of 3 comments by email and through the provided survey. Feedback was received from the Czech Republic, US and Argentina.

Summary of public comment

Actions noted in green.

Question: Is there anything important that we have not included or any errors that you have noted?

No additional studies or errors in the analysis were highlighted through the feedback.

Comments were received raising concern around the amount of evidence to support the use of azathioprine to treat MS.

During the guideline process, the panel have noted the limited quantity of evidence related to azathioprine and methotrexate, and included an applicable remark in the recommendations. These concerns will be addressed in the manuscript(s).

Question: Is there any context or background we should make sure to include in the final peer reviewed publication? Please include reasons why this particular point needs to be included or emphasized.

The following suggestions and comments were put forward for consideration:

- Ensure the message is short and clear, so that it is not necessary to search through the full documentation to understand the recommendations.

The panel will consider this feedback when drafting the manuscript(s).

- Concern raised about the definition of 'affordable' where health systems could stop providing other DMTs based on price.

We have updated the essential medicines FAQs to cover this topic, which was discussed in our off-label work (MOLT). Within our off-label work we extensively discuss this question around affordability, and it would be a misinterpretation of these guidelines to limit access to DMTs on the premise of cost. Affordability is a major barrier for access to treatment. In many countries DMTs are available in theory, but remain unaffordable for many people with MS.

- Question on whether there are situations where the use of azathioprine use can be justified, other than cost-saving to the healthcare system.

The Atlas of MS reported that 14% of countries globally do not have access to any on-label DMTs. We believe this is an underestimate, as a number of countries did not respond to the survey. In most low- and middle-income countries people with MS pay part or all of the costs of the DMTs themselves. Cost and affordability have been highlighted as a major barrier to access to treatment. We therefore believe that recommendations on the use of azathioprine are an important tool for clinicians and people with MS having to make difficult treatment decisions in low-resource settings.

Question: Do you have any suggestions on how these recommendations should be disseminated? Please share any relevant experience you may have from low-resource settings to help us consider implementation of these guidelines.

Feedback on dissemination included concern around the length of the document and complexity of standardised language used for straight-forward recommendations. Suggestion was made to make the message short and clear.

The MEMP panel will consider these comments when drafting the manuscript(s) to provide clear and accessible recommendations for both healthcare professionals and people affected by MS.