

# FOCAL-MS2 study: English translation, cross-cultural adaptation and validation of the French new patient-reported outcome measures of the Multiple Sclerosis Autonomy Scale (MSAS)



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## Introduction with objective

Multiple sclerosis (MS) is an inflammatory and degenerative demyelinating disease of the human central nervous system. Autonomy is recognized as one of the key contributor of health according to the WHO's (World Health Organisation) definition (1), but there currently is a lack of validated MS-specific tools to assess patient autonomy.

Many MS patients have symptoms that impact on their autonomy, defined as being able to perform the roles that are most important to oneself, with or without help.

MSAS is a new questionnaire (1), developed in French, that aims at evaluating patient autonomy in multiple sclerosis.

The objective of this research was to translate and cross-culturally adapt the MSAS in English.

## Methods

The adaptation process was meticulously conducted, adhering to international guideline (2) to ensure semantic, conceptual, and idiomatic equivalence with the original French version. The translation process addressed 35 items, included in six steps:

- Two forward translations by independent linguistic experts were compared, enabling detection of errors and divergent interpretation of ambiguous items in the original
- Reconciliation of the forward translations into a single forward translation
- Back translation of the reconciled translation into the source language
- Review and harmonization of the back translations against the source language
- Cognitive debriefing of the new translation with patients from the target population
- Finalization of the translation

Five patients participated in the qualitative cognitive interviews and pilot testing in May 2025, asking additional information regarding comprehension and clarity of each question, ease and adequation of possible answers.

Table 1: from original to translated questions

part 1	Dimension			Linguistic forward update	Patient Cognitive Debriefing update
		French version	English version		
<b>Quel niveau d'importance accordez-vous...</b>					
D1	au fait de pouvoir participer à des activités avec vos proches (ex : vos enfants, votre famille, vos amis,	to be able to participate in activities with your loved ones (e.g., your children, your family, friends, neighbors) ?		No	No
D2	au fait de pouvoir continuer vos activités professionnelles comme vous le souhaitez ?	to be able to continue your work-related activities as you want to?		No	No
D3	au fait d'être considéré par les autres au travail ?	to be regarded by others at work?		Yes	No
D4	au fait de contrôler l'image que vous renvoyez aux autres ?	to control the image you project to others?		Yes	No
D5	au fait de pouvoir trouver du soutien chez vos amis ?	to be able to get support from your friends?		No	No
D6	au fait de vous sentir pris en compte par vos soignants ?	to feel considered by your healthcare providers?		Yes	No
D7	au fait de vous sentir soutenu par votre partenaire ?	to feel supported by your partner?		No	No
D8	au fait d'accomplir votre rôle de grand-parent ?	to fulfill your role as a grandparent?		No	No
D9	au fait de pouvoir vous engager dans un club ou une association comme vous le souhaitez ?	to be able to be involved in a club or an association in the way you want to?		No	Yes
D10	souhaitez ?	to be able to take part in activities for yourself (sport, leisure activities, travel, etc.) <b>in the way</b> you want to?		Yes	Yes
<b>Au cours des 4 dernières semaines, ...</b>					
D1	à quel point avez-vous eu le sentiment de mener la vie que vous souhaitez ?	to what extent have you felt you <b>were</b> living the life that you wanted?		Yes	No
D1	vous avez pu aider vos proches comme vous le souhaitez.	you have been able to help your loved ones in the way you wanted to		No	No
D1	vous avez pu aider vos proches comme vous le souhaitez.	you have been able to move around in public places as you have wanted to.		No	No
D1	vous avez pu entretenir des relations satisfaisantes avec vos proches.	you have been able to maintain satisfactory relationships with your loved ones.		No	No
D2	y a-t-il eu des moments où vous vous êtes senti dévalorisé dans votre travail ?	have there been times when you have felt undervalued at work?		No	No
D2	y a-t-il eu des moments où vous avez craint de perdre votre emploi ?	have there been times when you were worried about losing your job?		No	No
D2	y a-t-il eu des moments où vous avez eu le sentiment de devoir vous surpasser pour faire votre travail ?	have there been times when you have felt you had to <b>surpass your limits</b> to do your job?		Yes	No
D3	y a-t-il eu des moments où vous avez limité vos activités dans des endroits publics par peur d'être jugé du fait de votre maladie ?	have there been times when you have restricted your activities in public places for fear of being judged because of your condition?		No	No
D3	y a-t-il eu des moments où vous avez cherché à cacher votre maladie lorsque vous vous trouviez dans des endroits publics (dans la rue,				
D4	à quel point vous êtes-vous senti soutenu par votre employeur ?	have there been times when you tried to hide your condition when you were in public places (in the street, in		No	No
D4	y a-t-il eu des moments où vous avez senti que votre employeur vous ménageait (par ex. en vous préservant, ou en adaptant votre travail) ?	to what extent have you felt supported by your employer?		No	No
D4	vous avez pu avoir des relations satisfaisantes avec vos collègues de travail.	have there been times when you felt that your employer was <b>going easy on you</b> (e.g., by protecting you or adapting your job)?		Yes	No
D5	y a-t-il eu des moments où vous êtes sentis soutenu par vos amis ?	you have been able to maintain satisfactory relationships with your work colleagues.		No	No
D5	a-t-il eu des moments où vous avez senti que vos amis vous ménageaient (par ex. en vous préservant...)	have there been times when you felt that your friends were making allowances for you (e.g., looking out for you, etc.)?		No	No
D5	y a-t-il eu des moments où vous avez senti vos amis touchés par votre maladie ?	have there been times when you felt your friends were affected by your condition?		No	No
D6	à quel point avez-vous eu le sentiment de participer activement aux décisions concernant votre santé ?	to what extent have you felt you were taking an active part in decisions about your health?		No	No
D6	y a-t-il eu des moments où vous vous êtes sentis compris et soutenus par vos soignants ?	have there been times when you felt understood and supported by your healthcare providers?		Yes	No
D7	vous êtes-vous senti(e) compris(e) et soutenu(e) par votre partenaire.	<b>have you felt</b> understood and supported by your partner?		Yes	No
D7	y a-t-il eu des moments où vous avez senti votre partenaire s'inquiéter de votre état de santé ?	have there been times when you felt your partner was worried about your health?		No	No
D8	à quel point avez-vous pu vous occuper de vos petits-enfants comme vous le souhaitez ?	o what extent have you been able to look after your grandchildren as you		No	No
D8	à quel point avez-vous pu être présent pour vos petits-enfants comme vous le souhaitez ?	Over the past 4 weeks, to what extent have you been able to look after your grandchildren in the way you wanted to?		No	No
D9	y a-t-il eu des moments où vous vous êtes senti(e) utile au sein d'un club ou d'une association ?	have there been times when you felt useful as part of a club or an association?		No	Yes
D9	à quel point avez-vous pu entretenir des relations avec les autres membres d'un club ou d'une	to what extent have you been able to maintain relationships with other members of a club or an association?		No	Yes
D10	vous avez commencé, repris ou poursuivi une activité sportive ou de loisir.	you have started, resumed, or continued a sporting or leisure activity.		No	No
D10	vos activités sportives ou vos loisirs vous ont permis de vous sentir mieux.	your sporting or leisure activities have helped you to feel better.		No	No

## Results

Following the translation from 2 independent linguistic experts and the back translation, 17 wording differences led to modifications of the questionnaire: 3 on the questionnaire description, 5 (out of 10) on the dimension labels and 9 (out of 35) items labels.

During the qualitative cognitive interviews, patients had no difficulty to understand the questions and these interviews led to modification of 8 items to improve their clarity to finalize the translation (in red on the Table 1).

Final proofreading led to 2 minor changes to be consistent with the wording throughout the questionnaire.

## Conclusion

Items were well understood by patients, with some revisions being incorporated after the cognitive interviewing based on feedback from the interviewees.

The translated MSAS now have linguistic and cultural equivalence to the original version and have demonstrated face validity. The English version of the MSAS is now available for further studies to evaluate autonomy burden.

### References:

(1) MSARD: [https://www.msard-journal.com/article/S2211-0348\(24\)00501-7/fulltext](https://www.msard-journal.com/article/S2211-0348(24)00501-7/fulltext)  
 (2) ISPOR guideline DOI: 10.1111/j.1524-4733.2005.04054.x

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