

To whom it may concern

O.R.: Mapi/Icon project #0165-tr-0010

Regarding: **Recruitment of Patients suffering from Multiple Sclerosis**

Lyon, 28 February 2019

Dear Madam, Dear Sir,

Mapi Language Services is an international company with a special interest in advancing the worldwide use of patient-reported and clinical assessments through linguistic validation for appropriate cross-cultural use and interpretation.

The linguistic validation aims at providing different Language versions of the same questionnaire, which are:

- culturally relevant in the target country
- conceptually equivalent to the original, ensuring cross-cultural equivalence across all «Language» versions
- employ Language expressions of common use accessible to everybody in the target country

Mapi has therefore developed a standardised, internationally recognised translation procedure. After many years of proven experience in multi-national projects in collaboration with more than 600 consultants throughout the world, we have developed a unique, well-established expertise in the field.

The translation procedure namely comprises a comprehension test on patients with the aim to test the understanding and acceptability of the translated questionnaire on a small panel of patients. All translations are carried out in the target country in collaboration with a native speaking local project manager.

We have recently been asked by one of our clients to translate the MSIS-29 and Abilhand questionnaires into English for New Zealand. Claire Loftus is our local project manager

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for this project, and she will need to recruit 5 patients suffering from Multiple Sclerosis in order to discuss the wording of this questionnaire during face-to-face interviews.

1- Why do we need to interview patients?

We have translated the questionnaire according to a very precise and complex process, involving several translators working under the guidance of Claire Loftus who will be performing the interviews.

As this questionnaire specifically addresses people suffering from Multiple Sclerosis, we would like to have the comments of people with the same condition on the wording of the questions and to know whether the questions are clear and easy to understand and if they reflect their experience correctly. According to what the patients tell us, we may modify the translation and improve it so that the people who use it later on will have no problems understanding it.

The patients' opinion on the wording of the questionnaire, on the words used and on the way the questions are formulated/asked is very important to us. Because they know particularly well what it is like to live suffering from Multiple Sclerosis and the way it influences their daily life, their insight will be of great help in producing a translation that reflects the way they feel and the way they talk about their condition. In a few months, this questionnaire will be filled in by many people suffering from Multiple Sclerosis in the context of medical research. By participating now, the patients play an important role in producing a document which will be clear and easy to understand for all those who use it in the future.

2- What will happen during the interviews?

First our local project manager will ask the patients to complete the questionnaire on their own. They should try to answer the questions as best and as honestly as they can. If they don't know how to answer a question, they should just leave it blank. This will allow us to see if the questionnaire is easy to answer or not.

Once the patients have filled in the questionnaire, our local project manager will then go through it with them and discuss various issues. During this discussion, the patients will be asked to give their impression of the questionnaire, and to explain how they understand various items and concepts. This discussion will enable us to see whether the questions in the questionnaire are appropriately worded or not. Our local project manager will audio-record or note down what the patients say, simply to keep a record of the discussions and because s/he will be interviewing several people with the same condition.

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3- What will be done with the information the patients will be giving?

We will make a synthesis of the comments of all patients participating in these interviews. On the basis of this global summary we will then be able to decide on the changes to be made to the translation.

Please note that although we will keep track of what the patients say, their name will never be associated with their comments and will not be recorded. In other words, the patients' participation in the interviews will remain completely anonymous.

Please also note that the interviews are totally independent from any medical research and that it will only be used in connection with the wording of the questionnaire. The information patients give us in relation to their condition during the interviews will remain confidential and will not be used for anything else other than judging whether the questionnaire is appropriate or not.

All information is important to us and we encourage patients to be talkative and to express what they feel about the questionnaire as freely as possible.

We thank you for your help.

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