

# Development of the Lifestyle and Preventative Health Index Value in Multiple Sclerosis (LIV-MS): Preliminary Findings

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## Background

- Previous research has shown that unhealthy lifestyle behaviors have been associated with several adverse health outcomes <sup>(1,2)</sup>, like symptom severity <sup>(3)</sup>, comorbidity <sup>(4)</sup>, increased disability <sup>(3)</sup>, and disease progression <sup>(5)</sup> in persons with multiple sclerosis (PwMS).
- Since lifestyle behaviors are modifiable, routine screening and interventions addressing these issues may help to mitigate negative health outcomes.
- However, there are limited options for lifestyle behavior measures that have been validated in multiple sclerosis (MS).
- Not only are most measures dedicated to one lifestyle behavior (e.g., physical activity), but none to date have been developed specifically for PwMS by PwMS.
- There are also no lifestyle measures validated in MS that also include preventative health behaviors, such as screening for cancer, diabetes, or high blood pressure.
- Assessing these lifestyle and preventative health behaviors routinely in the clinic have been highlighted as being of high importance by our patients, signaling the need for this work.
- While experts are involved in the development of new measures, patient stakeholders are often excluded during the development process.
- Patient stakeholder involvement can result in a more meaningful measure, as well as help researchers identify biases that may affect reliability and validity.

## Objectives

To develop a MS-specific lifestyle questionnaire called the Lifestyle and Preventative Health Index Value in MS (LIV-MS), through a patient advisory group (PT-AG: n=5) and professional advisory group (PRO-AG: n=5).

The questionnaire will encompass the following:

- Lifestyle behaviors (e.g., physical activity, diet, stress, smoking and alcohol use and sleep)
- Preventative health behaviors (e.g., cancer, blood pressure, and diabetes screenings)

## Methods

| <i>Stage of Development</i>                     | <i>Status</i>   |
|-------------------------------------------------|-----------------|
| Assemble PT-AG and PRO-AG                       | Completed Stage |
| Delineate the domains in the measure            | Completed Stage |
| Develop initial bank of test items              | Current Stage   |
| Evaluate content validity with PT-AG and PRO-AG | Future Stage    |
| Refine test items for psychometric evaluation   | Future Stage    |

Table 1: Stages of development of the LIV-MS questionnaire and status

### Examples of questions asked at the first round of AG interviews:

- What topics should be covered in a lifestyle and preventative health questionnaire for persons living with MS?
  - For PT-AG: Are there certain lifestyle behaviors that are important for you to be tracked as part of your clinical care?
  - For PT-AG: Are there certain preventative health behaviors that are important for you to be tracked as part of your clinical care?
  - For PRO-AG: Are there certain lifestyle or preventative health behaviors that you feel are important to capture for your clinical assessments? How are they currently assessed?
- What specific insights or information about your lifestyle or preventative health are you hoping to gain from the LIV-MS questionnaire once it is scored?

## Results

Professional advisory group members were interviewed first including a physical therapist, neurologist, dietitian, internist, and psychologist to determine what they feel would be most beneficial to include in a lifestyle and preventative health questionnaire.

Topics were then presented to five PRO-AG members in a one-hour interview.

The following topics came out as most important to cover in a lifestyle and preventative health questionnaire according to PT-AG's and PRO-AG's.

| <i>Lifestyle Topics</i>                      | <i>Preventative Health Topics</i>                                                                                          |
|----------------------------------------------|----------------------------------------------------------------------------------------------------------------------------|
| Diet including hydration                     | Medication management                                                                                                      |
| Physical Activity/weight management/function | Weight changes, heart rate, blood pressure                                                                                 |
| Alcohol use                                  | Attending healthcare appointments, including check ups and screenings (i.e., mammograms, skin checks, colonoscopies etc. ) |
| Sleep behaviors                              | Comorbidities-are they managed?                                                                                            |
| Social activity/work/interactions/support    | Social determinants of health including food insecurity and barriers to getting preventative health                        |
| Smoking status                               | Vaccinations-are they up to date?                                                                                          |
| Recreational drug use                        | Age-appropriate health screenings                                                                                          |
|                                              | Stress management/Mental health                                                                                            |

Table 2: Lifestyle and Preventative Health Topics

## Discussion

Next stages of the project include developing a pool of items, responses, and scoring system. After internally revising them, a second round of one-hour interviews with each AG member will be held to elicit feedback on the clarity and face validity of the proposed LIV-MS items, rank items by their level of relevance, as well as identify any gaps in content.

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