

**James Lind Alliance
Medically Not Yet Explained Symptoms (MNYES)
Priority Setting Partnership Survey**

Have you got 10 minutes to spare to help guide future research?

What are medically not yet explained symptoms?

Sometimes people can have long-lasting physical complaints where the cause cannot be explained by medical investigations or tests. These are called medically not yet explained symptoms (MNYES) or medically unexplained symptoms. Many people experience MNYES; it is thought that 10-30% of GP appointments are made in relation to MNYES.

Examples of symptoms that might occur in common MNYES are:

- Pain
- Fatigue
- Dizziness and/or fainting
- Heart palpitations
- Stomach or bowel problems
- Symptoms causing problems with movement (such as tremors, shakes and weakness)
- Unexplained blackouts, seizures or sudden loss of awareness

Who are we?

We are a group of patients, carers, clinicians, and researchers who want to improve the care and quality of life of patients with MNYES. The James Lind Alliance aims to help patients and health professionals find unanswered research questions.

This work is a collaboration between the James Lind Alliance, The University of York, The Clinical Center of Excellence for Body, Mind and Health (Tilburg), and Tilburg University. Prof Christina van der Feltz-Cornelis from the Department of Health Sciences at the University of York is leading the project. Dr. Jonathan Gower is JLA chair.

Why we would like your help?

We want to give

- patients
- their carers/relatives and
- healthcare professionals involved in the diagnosis and treatment of MNYES

a voice in deciding the questions focussed on MNYES that should be answered by research so that patients can benefit in the future. The survey will take approximately 10 minutes to complete, depending on the length of your answers. If you are unable to complete the survey in one sitting, you will be able to come back to complete it up to one week after starting it.

What will we do with your survey responses?

If you choose to take part in the survey, we will collate the answers you provided with other survey respondents. Once we have collated all the responses, we will ask

patients, carers/relatives, and healthcare professionals to prioritise which of these they think are the most important questions for future research. This ranking will allow research funders to know which questions need to be answered by future research studies.

By participating in this survey you give us, and partner organisations, permission to publish your answers for the Priority Setting Partnership. You cannot be identified from the information you provide in the survey.

Please click the arrow to take the survey.

**James Lind Alliance
Medically Not Yet Explained Symptoms (MNYES)
Priority Setting Partnership Survey**

We would like patients with MNYES, their carers/relatives, and healthcare professionals involved in the diagnosis and treatment of patients with MNYES to help us decide questions focussed on MNYES that should be answered by research studies.

Your knowledge and expertise is essential and most welcome in helping us identify the most important questions that need to be researched.

If you are unable to complete the survey in one sitting, you will be able to come back to complete it up to one week after starting it.

1. Which of the following best describes you?

- A person who has experienced or is experiencing medically not yet explained symptoms (MNYES)
- A caregiver or family member of someone who has experienced or is experiencing medically not yet explained symptoms (MNYES)
- A health professional
- Other (please describe)

If 'caregiver' is selected, the following question will appear:

Are you completing this survey on behalf of the person you care for?

- Yes
- No

If 'health professional' is selected, the following question will appear:

What is your job title?

[free text box]

2. What questions do you have about MNYES that you would like to see answered by research?

Please feel free to add as many questions as you like.

[free text box]

Information about you

We would like to know about who is answering our survey. This is so we can make sure everyone's ideas are included. These questions are not compulsory.

3. Do you identify as:

- Female
- Male
- Prefer to self-describe
- Prefer not to say

4. What is your age? (If you prefer not to answer, please leave blank)

[free text box]

5. Which country do you live in? (If you prefer not to answer, please leave blank)

[free text box]

6. What is your ethnicity?

- Asian/ Asian British
- Arab
- Black/Black British
- Mixed/Multiple ethnic groups
- White
- Prefer not to say
- Other (please describe)

7. Do YOU have or have YOU had MNYES?

- Yes
- No
- Prefer not to say

If 'Yes' is selected, the following questions will appear:

What medically not yet explained symptoms have you experienced?

Please select all that apply

- Pain
- Fatigue
- Dizziness
- Heart palpitations and/or fainting
- Stomach or bowel problems
- Symptoms causing problems with movement (such as tremors, shakes and weakness)
- Unexplained blackouts, seizures or sudden loss of awareness
- Other (please describe)

At what age did you first experience or develop medically not yet explained symptoms?

If you can't remember the exact age, please give an approximate age

[free text box]

If 'carer' was selected in the first question, the following questions will appear

Does the person you care for have or had MNYES?

- Yes
- No

If Yes, what MNYES have they experienced?

Please select all that apply

- Pain
 - Fatigue
 - Dizziness
 - Heart palpitations and/or fainting
 - Stomach or bowel problems
 - Symptoms causing problems with movement (such as tremors, shakes and weakness)
 - Unexplained blackouts, seizures or sudden loss of awareness
 - Other (please describe)
-

How did you hear about this survey? (e.g. Twitter, POTS-UK, word of mouth)
Please type your answer in the text box below.

[free text box]