

**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:

- Persistent pain
- Persistent 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.

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.

What is the survey for?

Last year we ran a survey asking people which questions about MNYES that they would like to see answered by research. We invited people living with MNYES, carers and health care professionals for their views. Thank you to everyone who sent in comments and questions. We've taken all the responses into account and summarised them into 46 representative questions. We now need your help to decide the most important questions to take forward.

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 all the other survey respondents. This will allow us to identify the questions that are most important to patients, carers/relatives, and healthcare professionals. These will then be taken forward to a workshop involving patients, carers/relatives, and healthcare professionals where the Top Ten questions will be decided. We would like to invite you to this workshop, more information is at the end of the survey. The Top Ten questions will help research funders to know which questions about MNYES need to be answered by future research studies.

What you can do to help

We would like you to select the 10 questions which matter to you the most from the list that follows. This is an anonymous survey, but we will also ask for a little information about you so that we can understand who is responding and whether we're reaching as wide a range of people as possible. All the questions in this section are optional. We won't be able to identify you in any of the survey results and we will keep the information you give us secure.

Please click the arrow to proceed to the questions.

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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 prioritise questions focused 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.

Here is the list of 46 summary questions from the survey we conducted last year.

Please select the 10 questions which matter the most to you.

(46 questions listed in a random order for each participant)

- Do childhood, recent or ongoing adverse events trigger or maintain MNYES?
- Which conditions/factors influence the development or onset of MNYES (such as age, gender, ethnicity, social factors, lifestyle, diet, infections, genetics)?
- What is the relationship over time between MNYES and known medical conditions and does that suggest some shared pathological process?
- Could different presentations of MNYES be explained by different mechanisms or causes?
- How many people are affected by MNYES?
- What are the mechanisms of MNYES and can we identify biomarkers for them?
- What is the relationship between mental health problems and MNYES?
- What symptoms are commonly reported by people with MNYES and what links them?
- Why do symptoms of MNYES fluctuate?
- How do patients/carers/healthcare professionals understand the symptoms of MNYES?
- What strategies are effective at promoting awareness and up to date clinical knowledge about MNYES amongst healthcare professionals?

- What are the most effective methods for training clinicians to diagnose and treat their patients with MNYES with compassion, empathy and respect?
- What is the impact of MNYES on healthcare utilisation?
- How can employers support people with MNYES?
- What is the best practice to offer optimal care for patients with MNYES?
- What is the current provision of services providing care and treatment for patients with MNYES?
- What are current clinical attitudes and levels of knowledge about MNYES?
- What are patient experiences of the treatment/support they have received for MNYES?
- How can clinicians collaborate effectively to form the most appropriate care pathway and service model to offer assessment and treatment for patients with MNYES?
- What aspects of multi-disciplinary treatment programmes are effective for MNYES?
- What is the impact of receiving and sharing an MNYES diagnosis for both patients and carers?
- How should information be shared with patients with MNYES and their carers throughout the diagnostic phase?
- What are the information needs for patients with possible MNYES related to diagnostic and treatment decisions, and how should this be provided?
- How valid and reliable are current diagnostic tools for MNYES and what are the limitations of testing?
- Which validated screening tools for emotional wellbeing/ quality of life are most useful for people with MNYES?
- How many people are misdiagnosed with MNYES and what are the consequences?
- How are MNYES related to disability?
- How can clinicians identify when a MNYES scenario is beginning to develop and provide information about this?
- Which self-management techniques are effective in MNYES?
- What can improve treatment engagement for patients with MNYES?
- What are the most effective pharmacological treatments for different MNYES symptoms?
- What are the most effective psychological treatments for different symptoms of MNYES?
- Overall, what are the most effective treatment strategies for different symptoms of MNYES?
- What are the most effective physical treatments for different symptoms of MNYES?
- Do treatments for co-existing psychiatric conditions impact on the symptoms of MNYES?
- How do treatments for MNYES work?
- How can the most appropriate treatment be selected, dependent on different MNYES symptoms, that a person with MNYES is most likely to benefit from?
- What are the most effective ways to support patients with MNYES and their carers to live with their symptoms?
- What is the prevalence of injury (physical and psychological) due to MNYES and/or its treatment?
- What factors affect outcomes for MNYES?
- What affect do MNYES have on mental health?
- What treatment factors affect outcomes for MNYES?
- What is the most appropriate way to measure treatment effect for MNYES?
- What outcomes matter most to patients with MNYES?
- What health service factors affect outcomes for MNYES?
- How do MNYES symptoms change over time?

Thank you. You indicated that the following questions matter most to you.

(Selected questions presented to participants for review)

If you would like to change any of the selected questions, please use the back arrow to return to the previous page.

If you are happy with your selection, please proceed to the rest of the survey.

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) [free text box]
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The following questions will help us understand who is responding to this survey and whether we're reaching as wide a range of people as possible.
All the questions in this section are optional.
We won't be able to identify you in any of the survey results and we will keep the information you give us secure.

Are you completing this survey on behalf of the person you care for? (carers only)

Yes

No

What is your job title? [free text box] (healthcare professionals only)

What medically not yet explained symptoms have you experienced? (person with experience of MNYES only)

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) [free text box]

At what age did you first experience or develop medically not yet explained symptoms? (person with MNYES only)

[free text box]

Does the person you care for have MNYES, or have they had MNYES in the past? (carers only)

Yes

No

If Yes, what MNYES have they experienced? (carers only)

- 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) [free text box]

Do you identify as:

- Female
- Male
- Prefer to self-describe: How do you define your gender? [free text box]
- Prefer not to say

What is your age? (If you prefer not to answer, please leave blank) [free text box]

Which country do you live in? (If you prefer not to answer, please leave blank) [free text box]

What is your ethnicity?

- Asian/ Asian British
- Arab

- Black/Black British
- Mixed/Multiple ethnic groups
- White
- Prefer not to say
- Other (please describe) [free text box]
-

Would you like to hear the outcome of the final 10 priorities?

Would you like to be part of the final selection workshop which will be held on 16th (PM) & 17th (AM) September 2021?

If so, please indicate and provide your name and email address below so that we can contact you with more details.

Your contact details will be kept confidential, saved securely and will be removed from our records at the end of the project.

I would like to **hear the outcome of the final 10 priorities** (please provide your name and email address) [free text box]

I would like to **be part of the final selection workshop** on the afternoon of 16th September and the morning of the 17th September 2021 (please provide your name and email address) [free text box]

It's really helpful to understand how to reach people who might want to be involved in similar projects. Please tell us how you heard about this survey:

[free text box]

We thank you for your time spent taking this survey. Your response has been recorded.