

MPE RESEARCH PARTICIPANT INFORMATION SHEET:

You are being invited to take part in a research project organised by Myeloma Patients Europe (MPE) that involves filling out a questionnaire, followed by an optional interview. The aim of the project is to examine the impact of AL amyloidosis on health-related quality of life of patients and to scope unmet medical needs and ways in which these could be addressed. Before you decide if you want to participate, please read the following information.

Why is this research project being conducted?

MPE is recruiting AL amyloidosis patients from across Europe for a research project aimed at better understanding the patient experience and perspective, as well as to map unmet medical and information needs. The project will involve up to 10 patients from across the countries represented by MPE.

Do I have to take part?

Participating in this study is voluntary. If you decide to take part, you must indicate your agreement at the end of this form. You are free to change your mind at any point and you do not have to provide a reason for withdrawing from the project. Not participating or choosing to withdraw will have no impact on your medical care.

What is the aim of the questionnaire and the interviews?

The information gathered from the questionnaire and during the interviews will help MPE to better understand the needs of patients and shed light on how MPE can best support our members to meet those needs through resources, education, and advocacy.

What does the study involve?

You will receive an email invite from MPE to fill out an online questionnaire (in the format of a SurveyMonkey survey). After you completed the questionnaire, MPE will contact you to offer the option of discussing the results via a Zoom call. This meeting will last up to 1 hour and will be attended by 2 staff member from MPE.

Will the interviews be recorded?

Interviews will be video recorded to ensure accurate data collection. The recordings will only be available to MPE staff and will be destroyed after the notes are prepared. Participants may choose to use a pseudonym in order to keep their real name from being displayed and recorded and may keep their cameras off in order to conceal their face. Participants may choose to change their displayed name at any time during the interview and may choose to turn off their camera at any time during the conversation.

Will my taking part in this project be kept confidential?

Yes, MPE will not name or list the research participants publicly and only MPE staff will have access to the survey results and recordings.

Why should I take part this study?

MPE uses a patient-centred approach and prioritises the most pressing needs of the patient community when making decisions about program expansion and development as well as resource allocation. Your experiences are important for MPE and the broader patient community.

What will happen to the results of the study?

The results will serve as the basis of a scientific publication in a peer reviewed journal. Any insights shared publicly will be anonymised and no quotes will be attributed to patients without their consent.

MPE RESEARCH PARTICIPANT CONSENT FORM:

1. I confirm that I have read and understand the information above. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. (All questions can be sent to info@mpeurope.org).
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I understand that my participation in this study will be confidential.
4. I understand that anonymised data may be shared publicly.
5. I understand that if some of my views are quoted in a report or otherwise published, this will be done anonymously unless I consent to be identified.
6. I understand that my views will be video recorded for the purpose of the study and made available only to the MPE staff taking notes and preparing the report.
7. I agree to take part in the study.