



CAR-T treatment focus group discussion

Horizon 2020 CARAMBA is a project consortium investigating an innovative immunotherapy for the treatment of multiple myeloma, known as Chimeric Antigen Receptor T-cell therapy (CAR-T). Through strategic collaboration with a wide-range of stakeholders, including Myeloma Patients Europe, the consortium aims to ensure the streamlined transition of CAR-T from the laboratory through to multiple myeloma patients in the clinic. As well as the clinical aspects, the project consortium will also collaborate on regulatory and access issues and on ensuring that patient preferences are utilised in the project.

Therefore, MPE is hosting a focus group involving two consecutive discussion topics one with patients to gather the patient perspective on the use of Patient Reported Outcomes (PRO) in CAR-T clinical trials and the other with patients and caregivers to understand their experience of the socioeconomic burden and impact on quality of life-related to CAR-T treatment and side effects. A report detailing the results of the focus groups will be presented to consortium members and published on open access platforms.

Please carefully read all of the information below before completing the registration form at the bottom of this page and agreeing to the terms of the focus group:

MPE CARAMBA FOCUS GROUP PARTICIPANT INFORMATION:

You are being invited to take part in a focus group organized by Myeloma Patients Europe (MPE) as part of the Horizon 2020 CARAMBA consortium. Before you decide if you want to participate, please read the following information.

Why has this focus group been organised?

MPE is hosting a focus group involving two discussion topics. The first discussion is for myeloma patients who have previously been or are currently enrolled in a CAR-T clinical trial. The aim of this discussion is to understand the relevance, timing and patient preference on PRO questionnaires for CAR-T clinical trials. The second discussion is for



myeloma patients who have previously been or are currently enrolled in a CAR-T clinical trial and myeloma patient carers. The aim of the second discussion is to understand the patient and caregiver socioeconomic burden of CAR-T.

Do I have to take part?

Participating in the focus group is voluntary. If you decide to take part, you must indicate your agreement at the end of this form. You are free to leave the focus group at any point and you do not have to provide a reason for leaving.

What is the aim of the focus group?

The information gathered during the focus group discussions will provide useful information on patient PRO preferences and patient and caregiver socioeconomic experiences which can be utilised by companies who are developing clinical trials for CAR-T in the future.

What does the focus group involve?

You will participate in a 3-hour focus group that will be hosted online through Zoom. The focus group will be split into two discussion topics, each lasting 75 minutes with a break in between. There will be up to 10 patients in the first discussion and up to an additional 5 carers in the second discussion as well as up to 3 MPE staff members. An MPE staff member will moderate the focus group, asking participants a series of questions related to their experience of PRO data or the socioeconomic burden of CAR-T treatment, while the other staff member(s) take notes, collect data, and provide technical support for participants when needed.

Both focus groups will be held according to participants availabilities.

Will the focus group be recorded?

The session will be video recorded to ensure accurate data collection. The recordings will only be available to MPE staff and a contracted transcriber 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 focus group and may choose to turn off their camera at anytime during the focus group.

Will my taking part in this focus group be kept confidential?

Yes, MPE will not name or list the focus group participants publicly and only MPE staff and the contracted transcriber will have access to the recordings.

Why should I take part in the focus group?

MPE uses a patient-centred approach and prioritizes the most pressing needs of the patient community when making decisions about programme expansion and development as well as resource allocation. Your experiences are important for MPE and the broader patient community. There is still much to learn to know how best to support patients during this pandemic and your insights will help us in our programme planning.

What will happen to the results of the focus group?

The results will be used internally by MPE to inform programme planning and resource allocation. MPE will also produce a public report of the findings to be shared online. Any insights shared publicly will be anonymised and no quotes will be attributed to patients without their consent. MPE may follow up with individual participants to schedule additional one-on-one interviews to gain further insights. Participation in any subsequent calls or communication following the focus group is voluntary.



MPE FOCUS GROUP 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 research@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 focus group 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 focus group and made available only to the MPE staff and a contracted transcriber preparing the report.
7. I understand that MPE cannot guarantee the disclosure information shared in this focus group discussion by other participants.
8. I agree to take part in the focus group.