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Information sheet

Patient Preferences for Multiple Myeloma Treatments: An Online Survey

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Dear Sir/Madam,

You are invited to participate voluntarily in an online survey that explores your preferences for multiple myeloma treatments. Before confirming your participation, we ask that you read this information sheet carefully. For questions about this study, please contact one of the people at the top of this page.

What is the purpose of this survey and what will my answers be used for?

To identify the treatment characteristics of multiple myeloma treatments that are important to you as a patient and to explore some of the current challenges in conducting these types of surveys. Your answers will be used to develop recommendations on how best to conduct these types of surveys in the future. In addition, the results of this study may be informative to health authorities, health professionals, researchers and pharmaceutical companies. Participation in this study does not change your current treatment in any way.

Who is conducting this study?

This study is carried out by researchers at the Belgian university *KU Leuven*. This study is carried out in the following countries (and centers): Belgium (KU/UZ Leuven), Romania (Clinica de Hematologie, Spain (H. Moises Broggi / ICO Hospitalet) and Finland. This study is part of a European project called *"Patient Preferences in Benefit Risk Assessments during the Drug Life Cycle (PREFER)"*. The PREFER project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under Grant Agreement No. 115966. This Joint Undertaking is supported by the Horizon 2020 Research and Innovation Program of the European Union and EFPIA. To carry out this research, KU Leuven receives funding from the European Horizon 2020 program from the European Commission. For more information about Horizon 2020, see: https://ec.europa.eu/programmes/horizon2020. For more information about PREFER see: https://www.imi-prefer.eu/.

Is this study scientifically and ethically justified?

This study was approved by the Ethics Committee UZ/KU Leuven (study number 'S64287'), the Clinical Institute Fundeni (study number 54223) and the Research Ethics Committee of the Bellvitge University Hospital (reference PR363/20). Ethics committees check whether the rights of participants during a study are respected by the researchers,

whether the balance between risks and benefits is favorable for the participants and whether the research is scientifically and ethically justified.

Is my participation mandatory?

Your participation is completely voluntary. You can decline to participate. Your decision whether or not to participate will not affect your current healthcare. While results from this study may be informative in decisions about whether or not to market a drug or to reimburse a drug, your answers will not lead to any immediate change in your own current health care or to a particular prescription.

What information is collected?

Your preferences for treatment characteristics, your personal characteristics (such as your age, gender, nationality, education, quality of life, living situation, work situation, date of diagnosis, current treatment, previous treatment, contact with patient organizations, chronic diseases and how easy or difficult it is for you to read medical information) and your feedback about the survey.

How long does it take to complete the survey?

About 40 minutes

How will my data be handled?

Your data will be processed in accordance with the European General Data Protection Regulation (AVG/GDPR). As the sponsor of the research, KU is the controller of your personal data that is processed in the context of the research. During recruitment, the principal investigator or a licensed research associate will send you an email. If you want to view, correct, update, restrict, oppose or delete your data, or if you want to receive an electronic copy of the data you have provided, you have the possibility to contact one of the researchers mentioned at the top of this form and provide your email address at the end of the survey. At the end of the survey, you also have the possibility to provide your email address so that the researchers can email you the summarised results of the study or questions they may have regarding your responses. This means that these academic researchers will know your identity, but no one else. The survey does not ask for your name or collect your IP address. Only researchers who analyse your responses can access your responses. Although the survey does not collect your name or IP address, there is a possibility that the researcher analyzing your answers may recognize you

through a combination of your answers (for example, to questions about your personal characteristics, your answers to open questions). Your answers will be "pseudonymised". This means that you are not identifiable from the results of the study; the results will not contain names or identifying elements and your personal characteristics will be grouped and summarized. Your data is stored on an online secure platform of the PREFER project called "*SharePoint*". Sharepoint is a web-based database used to store and exchange data in a protected environment. This online platform was set up by academic researchers from KU Leuven and is only accessible to the academic partners involved in the analysis of your data; only these researchers receive the necessary data to log in to Sharepoint.

How are the results of this research shared and disseminated?

Through scientific journals, through presentations at conferences or meetings. You are not identifiable from these results; we do not ask for your name, your personal characteristics are summarized as group characteristics and data transmitted will not contain names or identifying elements. The researchers will also share these results with PREFER partners. These partners include academic institutions, patient organizations, health technology assessment agencies, small and medium-sized enterprises, pharmaceutical companies and regulators. Data protection laws in these countries may be less protective than data protection laws in the European Economic Area (EEA). Transfers from the EEA to other countries, including the US, will be subject to standards set by the European General Data Protection Regulation (GDPR), national and local laws. Pharmaceutical companies and commercial partners of the PREFER project will only have access to results that do not identify you. Only in this way can pharmaceutical companies, which may or may not be part of PREFER, be informed of the results.

How long will my data be kept?

For at least 20 years after the end of the study.

What rights do I have with regard to my data?

To view, correct, update, restrict, oppose or delete your data, or to receive an electronic copy of the data you have provided, you must contact one of the people at the top of this form and you must provide your email address when asked for it in the survey. Your request for data deletion will be processed within 30 days of the confirmation of your request. Such request cannot be fulfilled in the event that the deletion achieves or seriously impedes the objectives of the investigation, or in the event that the regulations

and laws applicable to this investigation require that such information be retained. Please note that you will not be able to view some of the data until after the end of the investigation and a request to delete your personal data cannot be fulfilled in the event that regulations and legislation require your personal data to be retained. You can ask the persons at the top of this form to send your questions, concerns or complaints to the data protection officer of their institution. If you have any questions about how we use your data, please contact one of the people at the top of this form. If you have any special concerns or wish to file a complaint afterwards, please contact the KU Leuven privacy team at: privacy@kuleuven.be. You also have the right to lodge a complaint with the data protection authority in Belgium via email: contact@apd-gba.be or telephone: +32 (0) 2 274 48 00.

Any additional or future research outside the study must always be approved by a recognized Ethics Committee. You will always be informed about the concrete research questions for which your data will be used.

Thank you for your interest and participation!