

Life with myeloma – a member survey carried out by the Swedish Blood Cancer Association with the support of MPE (Myeloma Patients Europe)

In the spring of 2023, the Swedish Blood Cancer Association conducted an in-depth and supplementary survey on life with myeloma. This was possible thanks to a grant from the European myeloma organization MPE (Myeloma Patients Europe), which the Swedish Blood Cancer Association collaborates with. The interest in the survey was great and the survey resulted in a high response rate (around 70 percent), which indicates that these types of questions are of great interest among the association's members.

The in-depth survey from 2023 increases the understanding of the life situation of myeloma patients and complements the member survey on myeloma that was carried out during the summer of 2022. The purpose of the new survey was, among other things, to find out how important it is for myeloma patients to control various aspects of their disease, how they prioritize access to new treatments and participation in clinical studies, as well as their interest in being involved in care and treatment decisions.

The survey was emailed to members of the Swedish Blood Cancer Association and only those who had stated a diagnosis of myeloma belonged to the survey's target group. The survey was aimed at both myeloma patients and relatives of people with myeloma. 458 people responded to the survey, of which 89 percent were patients and 11 percent were relatives.

The Swedish Blood Cancer Association states that the in-depth myeloma survey from 2023 confirms the results of the previous large member survey from 2022. Some of the most important conclusions concern topics such as access to new innovative treatments as well as the great interest of myeloma patients to participate in clinical studies. These specific areas are very important to us who represent the Blood Cancer Association, and we engage in and practice strong interest policy activities regarding these topics.

In the in-depth survey, we were able to confirm that a very high amount, 80 percent, of myeloma patients and their relatives consider it extremely important to have access to new and innovative treatments, as well as to have the opportunity to participate in clinical studies. Due to the severity of the disease, study participation is also encouraged in the Swedish national myeloma guidelines. In our previous surveys however, we have seen that the actual number of patients participating in clinical studies is significantly lower. In the 2022 survey, this question was asked and only 15 percent of the respondents had been offered the opportunity to participate in a clinical study.

From the in-depth survey, we also received information on how many lines of treatment the responding myeloma patients had undergone. It turned out that 43 percent had undergone only one form of treatment (one line of treatment), while the remaining almost 60 percent had received several lines of treatment. Two out of ten responding patients, 20 percent, had undergone at least four different lines of treatment. Each new line of treatment can have a negative effect on the body and the general health condition. With each additional line of treatment, there is also the risk of worse response to given treatment, shorter treatment-free periods, impaired immune system, increased toxicity and co-morbidity.

It is therefore important for us at the Swedish Blood Cancer Association to inform our members about alternative treatments. For example, this refers to new innovative EU-approved immunotherapies such as CAR-T and bispecific antibodies. These treatments have now been the focus of research and are now developed in the field of myeloma, and they can potentially change the way myeloma is treated as a disease in the future. CAR-T, which is a potential one-time treatment given by a single infusion, thus stands in great contrast to the traditional treatments which are usually given over a long period of time and sometimes for several years. CAR-T is currently not recommended in Sweden for use in routine clinical care for myeloma, but patients can gain access to new treatments, for example via participation in clinical studies.

The survey also shows how important the quality of life is for myeloma patients, as well as the possibility of being able to control various aspects of their disease and how limited patients become in their everyday lives. Three out of

ten respondents (30 percent) state that their myeloma-associated symptoms and daily activities and quality of life are greatly affected by the disease. These areas become particularly important because myeloma today is an incurable and chronic disease that people still can live with for a long time. However, the myeloma disease can affect the life of the patient and their relatives to a great extent, and it is very important to achieve a good quality of life. We believe this can be enabled by effective treatments that result in as few side effects as possible, but also through good rehabilitation opportunities.

A common treatment in myeloma is stem cell transplantation. Usually, an autologous stem cell transplant is performed, where stem cells are collected from the patient in a stable stage of the disease, so-called remission. However, allogeneic stem cell transplantation, when cells are received from a donor, can also occur. Seven out of ten responding patients (70 percent) had undergone a stem cell transplant and just over 50 percent stated that they had experienced several stressful side effects in relation to their stem cell transplant. Just over 25 percent stated that side effects from the stem cell transplant had a major impact on their general well-being and quality of life. With all treatments, even new and innovative therapies, there is a risk of side effects. The Swedish Blood Cancer Association however believes strongly that the future focus must be on research and implementation of effective treatments, which have as limited side effects as possible for blood cancer patients including myeloma patients, especially over time, so that a good quality of life can be achieved for this patient group.

A significant proportion (36 percent) believe that the new potential one-time single infusion treatment and immunotherapy CAR-T is important and can improve the health and well-being of myeloma patients. It also appears that about half of the respondents (53 percent) feel unsure about CAR-T treatment, because it is new and unknown to them. Therefore, it is important for the Blood Cancer Association to inform and increase knowledge about new treatment options, including CAR-T and bispecific antibodies.

A clear majority of the responding myeloma patients, 70 percent, want to be involved in treatment decisions. It is important that patients are given the right conditions and can receive adequate information from the healthcare staff about different treatment options, so that those who wish can participate and be involved in their own care. This means that more information is needed about the various treatment options that currently are and also will become available to patients in Sweden. The possibility of participating in clinical studies should also be discussed with every patient. This information needs to be given to a greater extent by healthcare professionals when discussing with the patient, so that patients can be given the opportunity and the right conditions to be involved in their care.

In our myeloma survey from 2022, a majority (six out of ten) answered that they learn about new treatments such as CAR-T and bispecific antibodies through the Swedish Blood Cancer Association's website and other communication channels. Only four out of ten answered that they had received that information from healthcare professionals.

Based on the background knowledge of myeloma patient respondents at the time of our most recent myeloma survey, one in four (25 percent) would choose CAR-T as their next treatment option. Five percent would choose a treatment with so-called bispecific antibodies and six percent would choose a stem cell transplant. About four out of ten (39 percent) have a great confidence in their treating physician and would choose the treatment option that he or she suggests.

Seven percent of the respondents in the survey were relatively young, between 35 and 54 years old, while just under half (42 percent) were between 65 and 74 years old. Slightly more women (53 percent) than men responded to the survey, but it is slightly more common for men to be diagnosed with myeloma.

The Swedish Blood Cancer Association greatly appreciates and want to thank Myeloma Patients Europe for this year's MPE scholarship, which made this in-depth myeloma survey possible. With increased evidence-based knowledge, the Swedish Blood Cancer Association can continue its successful public opinion and interest policy work to influence decision-makers, the industry and healthcare professionals so that myeloma care becomes even better for today's and tomorrow's myeloma patients.

Stockholm, Sweden 2023-12-22

The Swedish Blood Cancer Association