



MYELOMA  
EURONET

**Myeloma Euronet**  
**INTERNATIONAL SURVEY –**  
**MYELOMA TREATMENT SIDE EFFECTS**  
**AND UNMET PATIENT NEEDS 2009**

**S U M M A R Y R E P O R T**

*Myeloma Euronet, a non-profit network organization of multiple myeloma patient groups, is a European initiative dedicated to raising the awareness of multiple myeloma, an increasingly common form of bone marrow cancer. Myeloma Euronet provides information on the diagnosis, treatment and care of persons living with multiple myeloma and supports its member organisations in the fulfilment of their missions. Myeloma Euronet also advocates, both independently and in collaboration with organisations with similar objectives, on behalf of those affected by multiple myeloma.*

**Purpose:** This survey was designed to find out about, and compare, the opinions of healthcare professionals (physicians and nurses) and patients and patient relatives/caregivers regarding myeloma treatment side effects and potential unmet patient needs. Survey results will be used to help encourage national and international health care leaders and political decision-makers to focus greater attention on the appropriate treatment and care for myeloma patients.

**Methods:** The survey was conducted between February and July 2009 during several international congresses, including the XIIth International Myeloma Workshop in Washington, D.C., USA (26 February - 1 March 2009), the 35th EBMT congress and 3rd EBMT Patient & Family Day in Göteborg, Sweden (28 March - 1 April 2009), the 2nd International Lymphoma - Leukemia - Myeloma (LLM) Congress in Istanbul, Turkey (21-24 May 2009), and the 14th Congress of the European Hematology Association in Berlin, Germany (4-7 June 2009), and via postal questionnaire distribution through, and at local educational meetings of, Myeloma Euronet's member organisations. The survey was also available on the network's Web site at [www.myeloma-euronet.org](http://www.myeloma-euronet.org) (25 February - 5 July 2009). It consisted of a self-administered questionnaire with nine questions that took about 5-10 minutes to complete. Quantitative data analysis and evaluation were structured by questions and groups of participants which were subdivided into healthcare professionals (physicians/nurses) and patients and patient relatives/caregivers.

**Groups of participants:** In all, 314 healthcare professionals from 43 countries (240 or 76.4% from European countries) and 260 myeloma patients, patient relatives and caregivers from 21 countries of treatment (249 or 95.8% from European countries) have participated in the survey.

Healthcare professionals were subdivided into 241 physicians from 41 countries (217 haematologists (70.2%), 15 medical oncologists (4.9%), 8 haematologists-oncologists (2.6%)), 68 nurses (22%) from 19 countries, and 5 other healthcare professionals (not included in the evaluation).

Almost 95% of the physicians (94.6%) and three-quarters of the nurses (75%) were between 30 and 69 years of age. Of the physicians, 114 were male (47.3%) and 125 female (51.9%). Of the nurses, 11 were male (16.2%) and 57 female (83.8%). 2 physicians and 3 nurses did not indicate their gender.

Survey participants representing patient views were subdivided into 173 myeloma patients from 17 countries of treatment (66.5%) and 85 myeloma patient relatives (32.7%) and 2 caregivers (0.8%) participating on behalf of myeloma patients from 13 countries of treatment. Of the myeloma patients represented in the survey, 32 (12.3%) were below 50 years, 93 (35.8%) were between 50 and 59 years, and 124 (47.7%) were 60 years and above. 11 patients (4.2%) did not indicate their age. About half of the patients were male (121 or 46.5%) and 117 female (45%). 22 patients (8.5%) did not indicate their gender.

It should be noted that the opinions expressed by myeloma patients, patient relatives and caregivers may include a potential bias, as 108 participants (41.5%) were from Poland (63 patients (24.2%) and 45 relatives and caregivers (17.3%)). For this reason, responses to all survey questions were also checked for potential significant differences between answers from myeloma patients, patient relatives and caregivers from Poland and those of myeloma patients, patient relatives and caregivers from other countries.

**Sponsor:** This survey was made possible through an unrestricted grant from Ortho Biotech, Biopharmaceutical Division of Janssen-Cilag.

## SUMMARY OF RESULTS

### Introductory remark

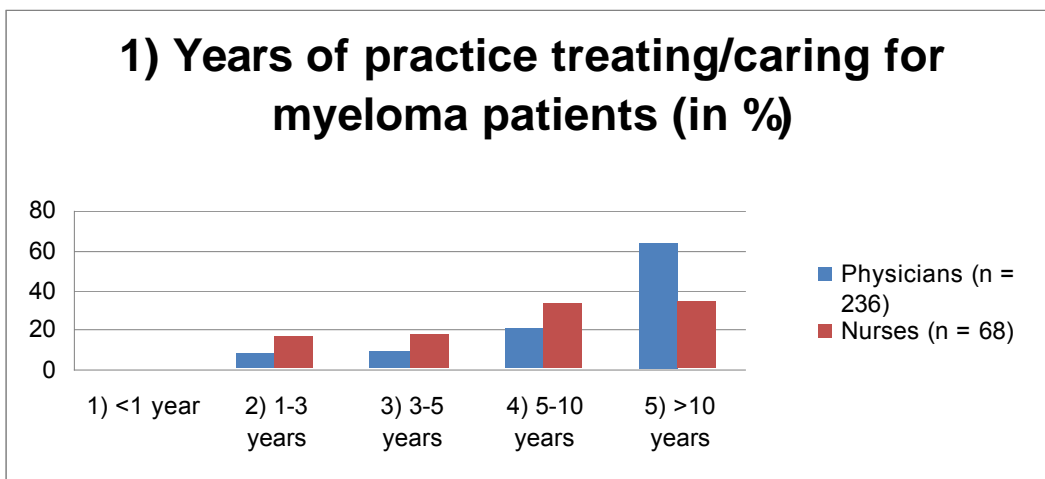
Because of the comparatively small number survey participants, this survey cannot be considered as representative of the thoughts and opinions of all myeloma patients and healthcare professionals across Europe. The uneven distribution of participant groups across countries also does not allow comparing opinions expressed by physicians and nurses with those of patients and relatives from one and the same country. However, this survey does allow drawing some conclusions regarding the thoughts and opinions expressed by physicians/nurses on one side and myeloma patients/relatives/caregivers on the other side, especially in cases where thoughts and opinions are shared or reveal significant differences.

### Question 1 for physicians/nurses:

**“For how long have you been treating/caring for myeloma patients?”**

(1) = Less than 1 year; 2) = 1-3 years; 3) = 3-5 years; 4) = 5-10 years; 5) = More than 10 years)

More than three-quarters of physicians (83.1%) and two-thirds of nurses (66.2%) who have responded to this question stated that they had been treating/caring for myeloma patients for more than 5 years.



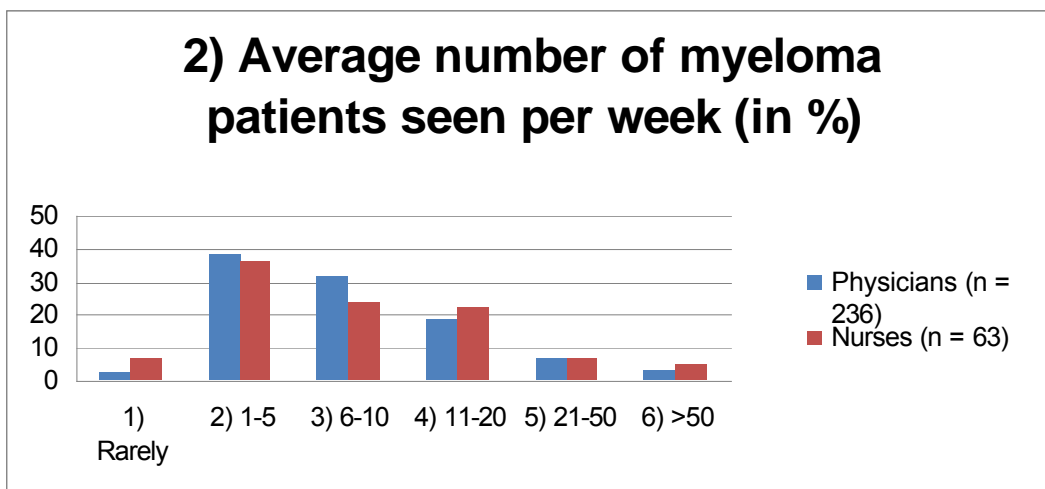
Graph 1) Years of practice treating/caring for myeloma patients (in %)

### Question 2 for physicians/nurses:

**“On average, how many myeloma patients do you see in one week?”**

(1 = I rarely see myeloma patients; 2) = 1-5; 3) = 6-10; 4) = 11-20; 5) = 21-50; 6) = More than 50)

About two-thirds of physicians (69.5%) and more than half of the nurses (60.3%) who have answered this question stated that they see 1-10 myeloma patients per week on average.



Graph 2) Average number of myeloma patients seen per week (in %)

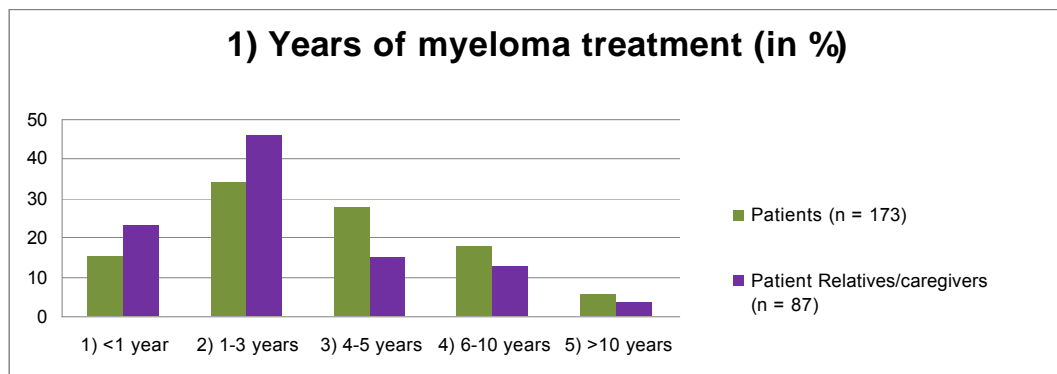
### **Question 1 for patients/patient relatives/caregivers:**

“For how long have you (has your family member) received myeloma treatment?”

(1) = Less than 1 year; 2) = 1-3 years; 3) = 4-5 years; 4) = 6-10 years; 5) = More than 10 years)

About half of the myeloma patients (49.1%) and more than two-thirds of the myeloma patients represented by their relatives or caregivers (69%) who responded to this question stated they had been receiving myeloma treatment for less than 1 year up to 3 years, and about half of myeloma patients (50.9%) and close to one-third of myeloma patients represented by their relatives or caregivers (31%) answered that they had been receiving myeloma treatment for more than 4 years.

Graphs illustrating the differences between myeloma patients, patient relatives and caregivers from Poland and myeloma patients, patient relatives and caregivers from other countries are shown in the “Additional Graphs” section at the end of this report.



Graph 3) Years of myeloma treatment (in %)

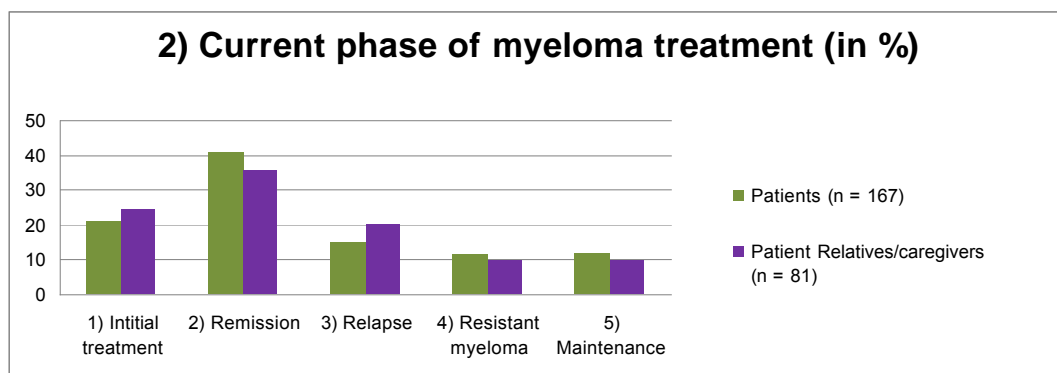
### **Question 2 for patients/patient relatives/caregivers:**

“Where do you (does your family member) stand in the course of myeloma treatment?”

(1) = Initial treatment; 2) = Remission; 3) = Relapse; 4) = Resistant myeloma; 5) = Maintenance

More than half of the myeloma patients (52.7%) and close to half of the myeloma patients represented by their relatives or caregivers (45.7%) who responded to this question stated they were either in remission or on maintenance treatment. About one-fifth of myeloma patients (21 %) and one-quarter of the myeloma patients represented by their relatives or caregivers (24.7%) stated they were receiving initial treatment, and more than one-quarter of myeloma patients (26.4%) and close to one-third of the myeloma patients represented by their relatives or caregivers (29.6%) stated they had a relapse or resistant myeloma.

Graphs illustrating the differences between myeloma patients, patient relatives and caregivers from Poland and myeloma patients, patient relatives and caregivers from other countries are shown in the “Additional Graphs” section at the end of this report.



Graph 4) Current phase of myeloma treatment (in %)

### Question 3:

– For healthcare professionals: “Which of the following treatments are used in your institution to treat myeloma patients?”

– For myeloma patients/relatives/caregivers: “Which of the following treatments have you (your family member) had during the course of your disease?”

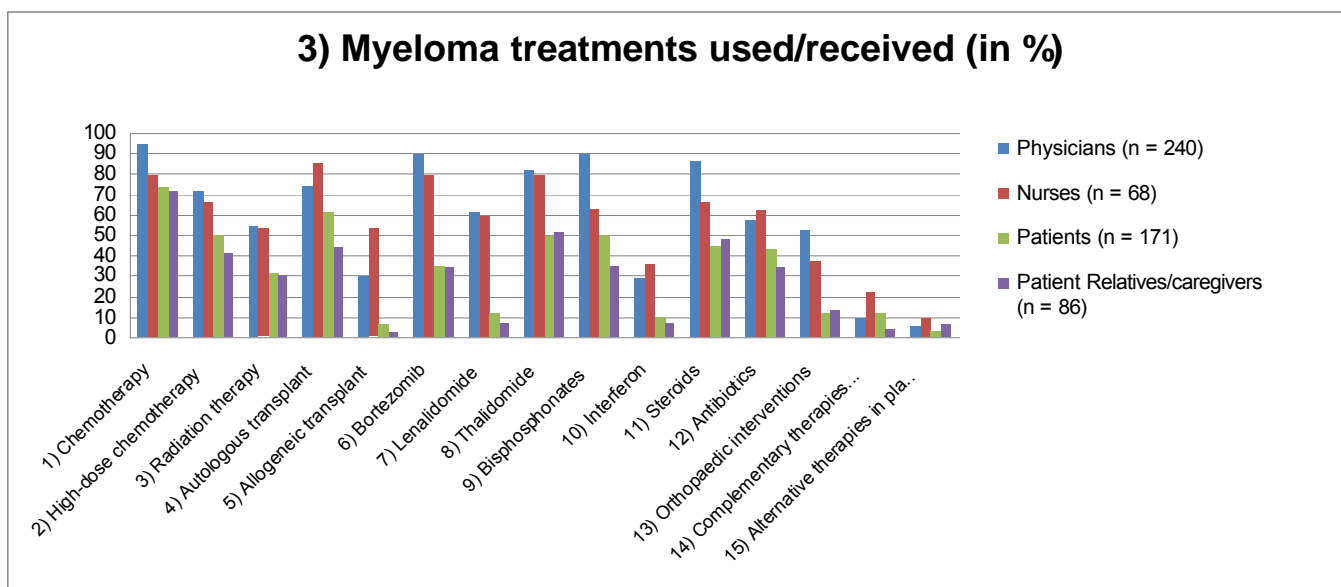
- 1) = Chemotherapy; 2) = High-dose chemotherapy; 3) = Radiation therapy; 4) = Autologous transplant;  
5) Allogeneic transplant; 6) = Bortezomib (Velcade); 7) = Lenalidomide (Revlimid); 8) = Thalidomide;  
9) = Bisphosphonates; 10) = Interferon; 11) = Steroids; 12) = Antibiotics; 13) = Orthopaedic interventions  
14) = Complementary therapies along with standard medical treatments;  
15) = Alternative therapies in place of standard medical treatments

It was possible to tick more than one answer option.

According to the physicians who answered this question, the most frequent myeloma treatment option used was chemotherapy (95%), followed by Bortezomib and bisphosphonates (89.2% each), steroids (86.3%), and Thalidomide (82.1%). According to nurses, the most frequent myeloma treatment option used was autologous transplant (85.3%), followed by chemotherapy, Bortezomib and Thalidomide (79.4% each), steroids and high-dose chemotherapy (66.2% each).

According to the myeloma patients who responded to this question, the most frequent myeloma treatment option received was chemotherapy (73.7%), followed by autologous transplant (61.4%), high-dose chemotherapy (50.3%), bisphosphonates (49.7%), and Thalidomide (49.1%). According to the myeloma patient relatives and caregivers who answered this question, the most frequent myeloma treatment option received by the patients they were representing in this survey was chemotherapy (70.9%), followed by Thalidomide (51.2%), steroids (47.7%), autologous transplant (44.2%) and high-dose chemotherapy (40.7%).

Graphs illustrating the differences between myeloma patients, patient relatives and caregivers from Poland and myeloma patients, patient relatives and caregivers from other countries are shown in the “Additional Graphs” section at the end of this report.



Graph 5) Myeloma treatments used/received (in %)

### Question 4:

– For healthcare professionals:

”Would you say that your patients are well informed about potential side effects of myeloma treatment options?”

– For myeloma patients/relatives/caregivers:

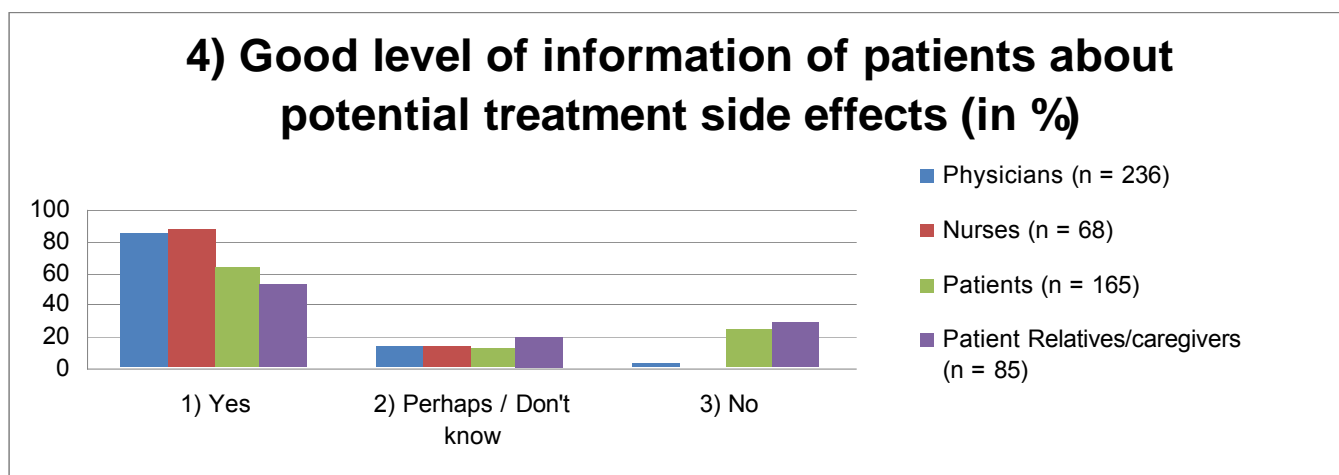
”Would you say that you were (your family member was) appropriately informed about potential side effects of myeloma treatment options by your (your family member’s) doctor?”

1) = Yes; 2) = Perhaps/Don't know; 3) = No

The majority of physicians (84.3%) and nurses (86.8%) who have responded to this question stated that they felt their patients were well informed about potential side effects of myeloma treatment options, but less than two-thirds of myeloma patients (63.6%) and just over half of patient relatives and caregivers (52.9%) stated that they felt they (or the patients they represented in this survey) were appropriately informed about potential side effects of myeloma treatment options by their (family member's) doctor.

Almost one in four myeloma patients (24.2%) and more than one-quarter of patient relatives and caregivers (28.2%) who have answered this question said that the patients they represented in this survey were not appropriately informed about potential side effects of myeloma treatment options by their doctor.

Graphs illustrating the differences between myeloma patients, patient relatives and caregivers from Poland and myeloma patients, patient relatives and caregivers from other countries are shown in the "Additional Graphs" section at the end of this report.



Graph 6) Good level of information of patients about potential myeloma treatment side effects (in %)

#### **Question 5:**

– For healthcare professionals:

“In the following overview, please tick those myeloma treatment side effects that you feel have the most negative impact on a myeloma patient’s overall well-being.”

– For myeloma patients/relatives/caregivers:

“In the following overview, please tick those myeloma treatment side effects that you feel have the most negative impact on a myeloma patient’s overall well-being and please underline those that you have (your family member has) experienced while undergoing myeloma treatment.”

1) = Nausea and vomiting; 2) = Hair loss; 3) = Mouth problems (sore mouth/lips, mouth ulcers); 4) = Infections, incl. influenza, pneumonia, etc.; 5) = Decreased appetite, weight loss; 6) = Effects on the stomach and/or colon, incl. obstipation, diarrhea, mucositis (inflammation of membranes lining the digestive tract); 7) = Fatigue, malaise, weakness, dizziness, somnolence, sedation, insomnia; 8) = Respiratory problems, incl. difficulty breathing, shortness of breath; 9) = Decreased body function, incl. loss/lack of strength, sexual activity, lack of mobility; 10) = Depression and anxiety; 11) = Fever; 12) = Muscle cramps, tremor (trembling or shaking); 13) = Kidney problems; 14) = Pain, incl. headache, pain associated with neuropathy, etc.; 15) = Neuropathy (nerve disorder that can result in abnormal or decreased sensation, or burning/tingling. When hands and feet are affected, it is referred to as peripheral neuropathy.); 16) = Hand-foot syndrome (tingling/burning, redness, flaking, swelling, blisters, or sores on the palms of the hands or soles of the feet); 17) = Skin problems, incl. rash; 18) = Bruises; 19) = Edema (abnormal accumulation of fluid beneath the skin, or in one or more cavities of the body); 20) = Increased bleeding due to shortage of blood platelets (thrombocytopenia); 21) = Blood pressure and heart problems, incl. slow heart action (bradycardia), heart rhythm failures, and low blood pressure (hypotension); 22) = Other blood problems, incl. shortage of red or white blood cells (anaemia or neutropenia) and high blood sugar (hyperglycaemia); 23) = Thrombotic events, incl. deep vein thrombosis (blood clot in one of the deep veins in the body) and pulmonary embolism; 24) = Damage to the jawbone (osteonecrosis); 25) = Graft-versus-host disease (transplant complication where donor immune cells attack the recipient’s cells)

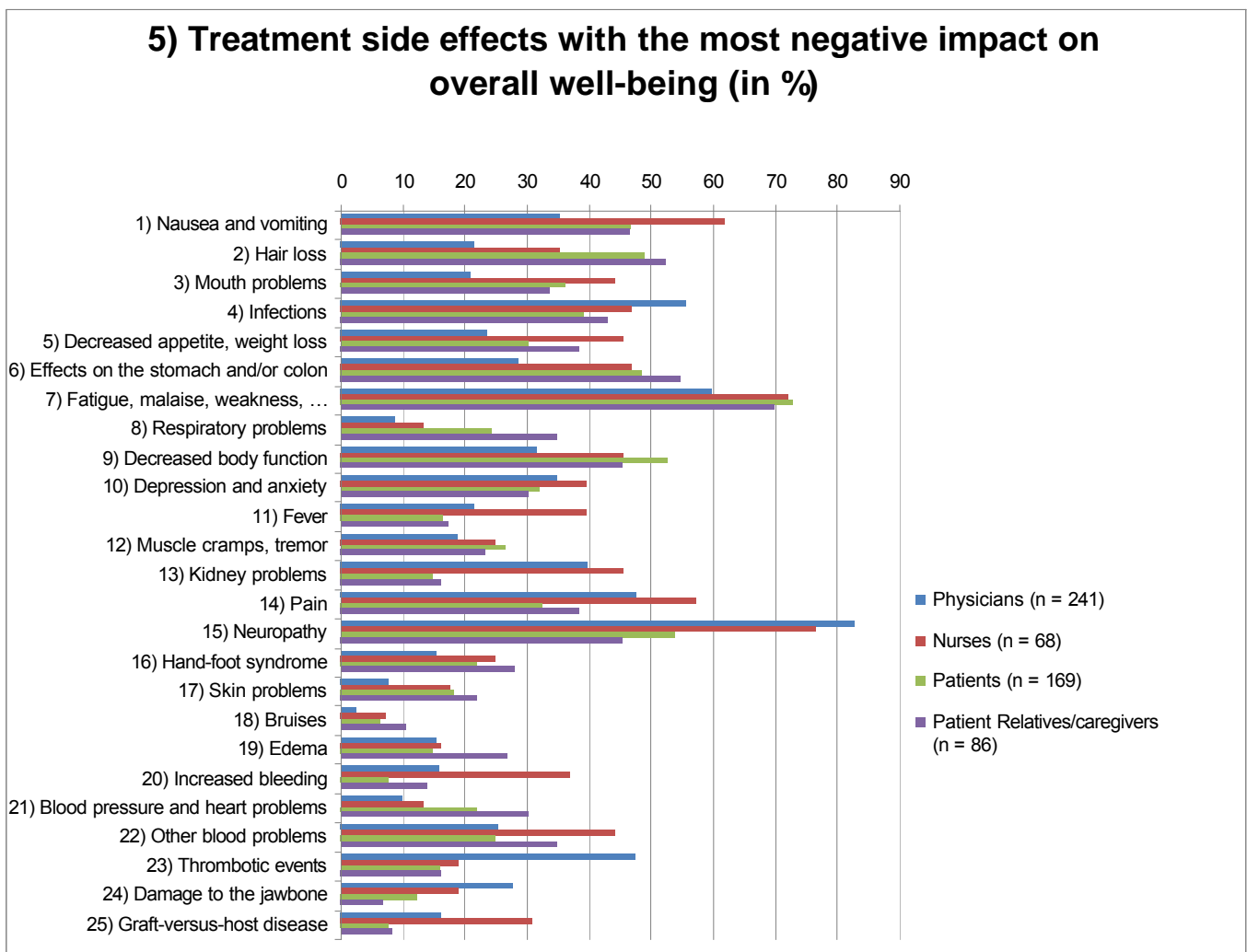
It was possible to tick more than one answer option.

According to the physicians and nurses who responded to this question, neuropathy has the most negative impact on a myeloma patient's overall well-being (82.6% and 76.5% respectively), followed by fatigue/malaise/weakness/dizziness/somnolence/sedation/insomnia (59.8% and 72.1% respectively).

Physicians stated that infections had the third-most negative impact on a myeloma patient's overall well-being (55.6%), followed by pain (47.7%) and thrombotic events (47.3%), whereas nurses responded that the third-most negative myeloma treatment side effect concerning a patient's overall well-being was nausea and vomiting (61.8%), followed by pain (57.4%), infections, and effects on the stomach and/or colon (47.1% each).

According to the patients and patient relatives and caregivers who answered this question, the myeloma treatment side effect with the most negative impact on a myeloma patient's overall well-being is fatigue/malaise/weakness/dizziness/somnolence/sedation/insomnia (72.8% and 69.8% respectively). Myeloma patients responded that the second-most negative myeloma treatment side effect concerning a patient's overall well-being was neuropathy (53.9%), followed by decreased body function (52.7%), hair loss (49.1%), and effects on the stomach and/or colon (48.5%), while patient relatives and caregivers stated that effects on the stomach and/or colon had the second-most negative impact on a myeloma patient's overall well-being (54.7%), followed by hair loss (52.3%), nausea and vomiting (46.5%), decreased body function, and neuropathy (45.4% each).

Graphs illustrating the differences between myeloma patients, patient relatives and caregivers from Poland and myeloma patients, patient relatives and caregivers from other countries are shown in the "Additional Graphs" section at the end of this report.



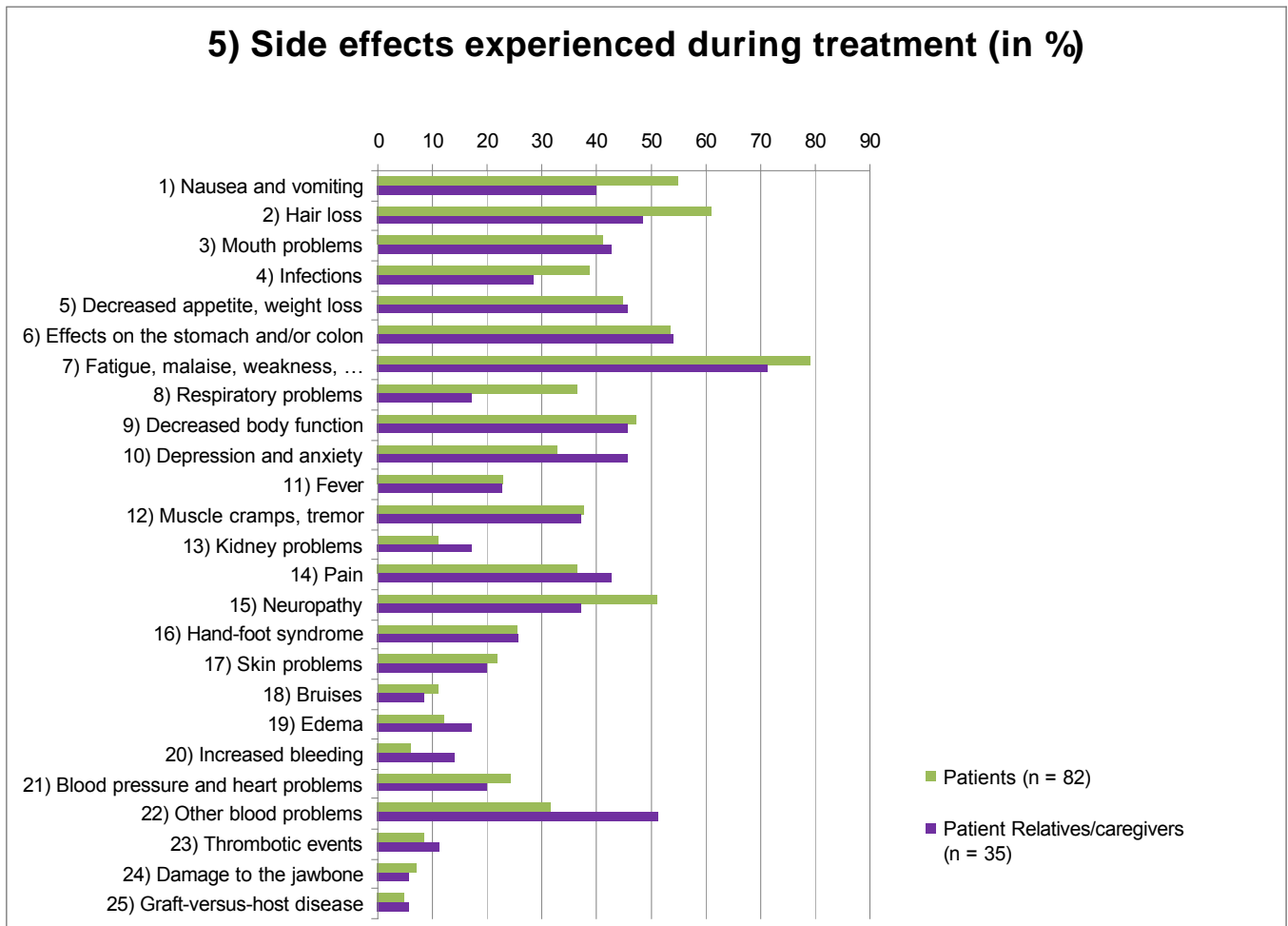
Graph 7) Myeloma treatment side effects with the most negative impact on overall well-being (in %)

When asked about the myeloma treatment side effects experienced while undergoing myeloma treatment, less than 50% of the patients and patient relatives and caregivers who had expressed their opin-

ions in the previous question responded (82 and 35 respectively). According to both groups of participants, fatigue/malaise/weakness/dizziness/somnolence/sedation/insomnia is the most frequently experienced myeloma treatment side effect (79.3% and 71.4% respectively).

According to myeloma patients, hair loss is the second-most frequently experienced treatment side effect (61%), followed by nausea and vomiting (54.9%), effects on the stomach and/or colon (53.7%), and neuropathy (51.2%). According to patient relatives and caregivers, the effects on the stomach and/or colon constitute the second-most frequently experienced myeloma treatment side effect (54.3%), followed by other blood problems (incl. shortage of red or white blood cells (anaemia or neutropenia) and high blood sugar (hyperglycaemia), 51.4%), hair loss (48.6%), decreased appetite/weight loss, decreased body function, and depression and anxiety (45.7% each).

Other blood problems appear to be an issue especially for myeloma patients in Poland. Graphs illustrating the differences between myeloma patients, patient relatives and caregivers from Poland and myeloma patients, patient relatives and caregivers from other countries are shown in the “Additional Graphs” section at the end of this report.



Graph 8) Side effects experienced during myeloma treatment (in %)

**Question 6:**  
 – For healthcare professionals:  
 “Are you satisfied with how myeloma patients manage the side effects that they have experienced?”  
 – For myeloma patients/relatives/caregivers:  
 “Are you satisfied with how the doctor has managed any side effects that you have (your family member has) experienced?”

1) = Very satisfied; 2) = Quite satisfied; 3) = Not really satisfied; 4) = Not satisfied at all;  
 5) = If you are not (really) satisfied, please state why not: ...

More than two-thirds of physicians (67.2%) and more than three-quarters of nurses (83.8%) who responded to this question were “very satisfied” or “quite satisfied” with the way myeloma patients manage the side effects they have experienced, and around two-thirds of patients (69.5%) and patient relatives and caregivers (63.1%) who responded to this question were “very satisfied” or “quite satisfied” with how their side effects were managed by the doctor.

However, about one-third of the physicians (32.8%) and about one in six nurses (16.2%) were “not really satisfied” or “not satisfied at all” with how myeloma patients manage the side effects they have experienced. And about one-third of patients (30.5%) and more than one-third of the patient relatives and caregivers (36.9%) stated that they were “not really satisfied” or “not satisfied at all” with how the doctor has managed any side effects experienced during myeloma treatment.

Of those survey participants who stated that they were “not really satisfied” or “not satisfied at all,” 29 physicians (38.2%), 1 nurse (9.1%), 32 myeloma patients (62.7%) and 21 patient relatives/caregivers (67.7%) also provided reasons for not being (really) satisfied with the management of side effects by the patient or the doctor. The most frequent reasons given by physicians included difficulties in treating side effects (44.8% of the physicians who stated reasons for not (really) being satisfied), followed by difficulties in (successfully) treating myeloma (20.7%), and lack of (patient) information (10.3%).

The most frequent reasons given by patients included lack of information from the doctor (21.9% of the patients who stated reasons for not (really) being satisfied), followed by lack of responsiveness/interest from the doctor (15.6%), and lack of time (9.4%). The most frequent reasons stated by patient relatives and caregivers included lack of information from the doctor (47.6% of the patient relatives and caregivers who stated reasons for not (really) being satisfied), followed by lack of competence from the treating physician (14.3%), lack of time, lack of continuity (not being treated by one physician), and lack of responsiveness/interest from the doctor (9.5% each).

The level of dissatisfaction in the Polish myeloma patient community was generally higher than in other countries. Graphs illustrating the differences between myeloma patients, patient relatives and caregivers from Poland and myeloma patients, patient relatives and caregivers from other countries are shown in the “Additional Graphs” section at the end of this report.



Graph 9) Healthcare professionals' satisfaction with patient management of side effects versus patients' satisfaction with doctor management of side effects (in %)

**Question 7:**  
 – For healthcare professionals:  
 “To what extent do treatment-related side effects affect myeloma treatment in your daily practice?”



1) = Often have to stop treatment; 2) = Often have to modify dosing; 3) = Don't know; 4) = Not at all

– For myeloma patients/relatives/caregivers:

“To what extent/how have treatment-related side effects affected your (your family member’s) course of myeloma treatment?”

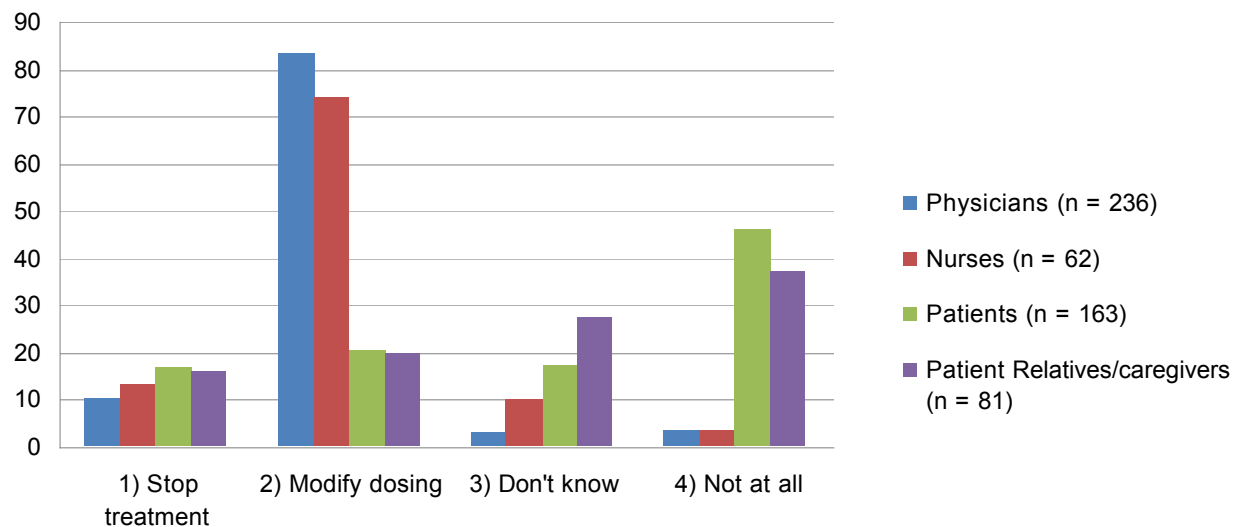
1) = Had to stop treatment; 2) = Had to modify dosing; 3) = Don't know; 4) = Not at all

When asked about the extent to which they feel treatment-related side effects affect myeloma treatment, about one in ten physicians (10.2%) and nurses (12.9%) who responded to this question stated that myeloma treatment often had to be stopped because of those side effects and about three-quarters of both groups (83.5% of physicians and 74.2% of nurses) said that it was often necessary to modify dosing because of treatment-related side effects.

The majority of myeloma patients who answered this question said that treatment-related side effects had no effect at all on their respective course of treatment (46%), a point of view also shared by more than one-third of the patient relatives and caregivers (37%) who responded to this question. About one in six patients and patient relatives and caregivers (16.6% and 16.1% respectively) stated that myeloma treatment had to be stopped because of treatment-related side effects and about one in five patients and patient relatives and caregivers (20.3% and 19.8% respectively) said that the dosing of the medication had to be modified due to those side effects.

Graphs illustrating the differences between myeloma patients, patient relatives and caregivers from Poland and myeloma patients, patient relatives and caregivers from other countries are shown in the “Additional Graphs” section at the end of this report.

## 7) Effect of treatment-related side effects on myeloma treatment (in %)



Graph 10) Effect of treatment-related side effects on myeloma treatment (in %)

### Question 8:

“Are you aware of any treatment-related side effects that myeloma patients don't feel comfortable reporting to their doctor? Please list them below and also state what you think are potential reasons:”

1) Treatment side effects not or rarely reported: ... 2) Potential reasons for not reporting them: ...

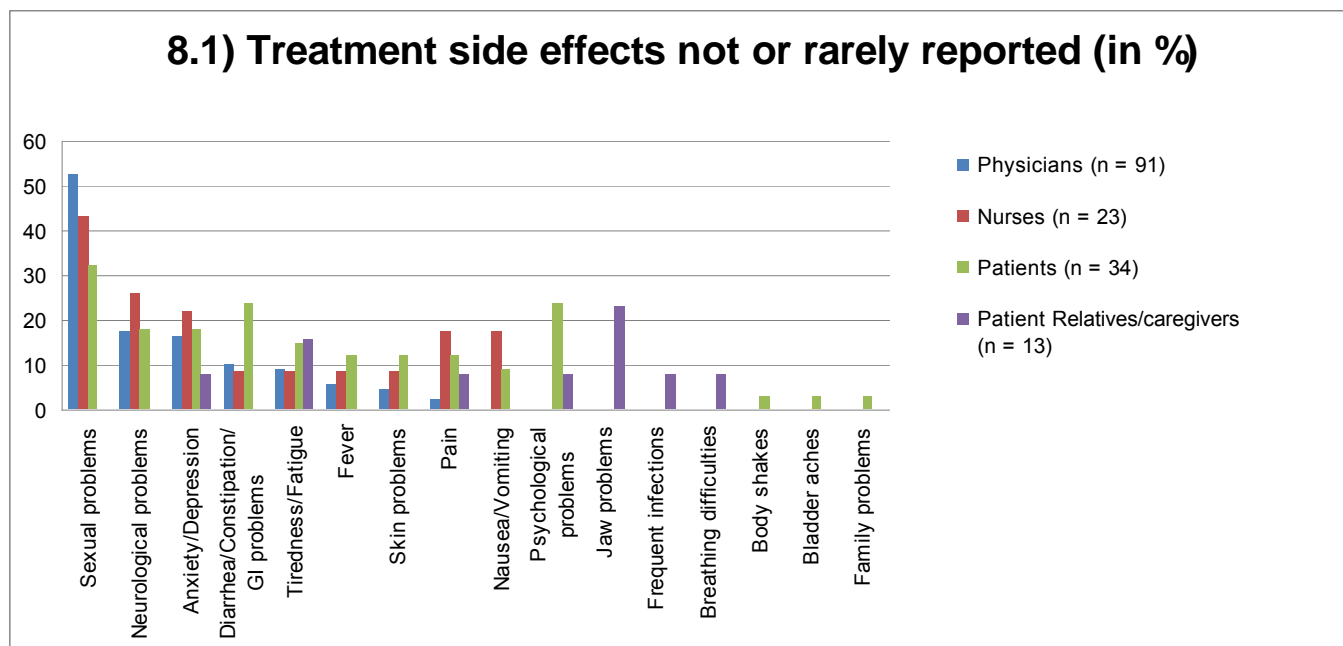
#### Question 8.1) Treatment side effects not or rarely reported

According to the physicians and nurses who responded to this question, the most frequent treatment-related side effects that myeloma patients don't feel comfortable reporting to their doctor include sexual problems (52.8% and 43.5% of answers respectively), neurological problems (17.6% and 26.1%) and anxiety/depression (16.5% and 21.7%). One in five nurses also stated that patients don't feel comfortable addressing pain and nausea/vomiting with their doctor (17.4% each). Other treatment-related side effects which physicians and nurses felt patients tend to avoid mentioning when talking to their doctor included diarrhea/constipation/gastro-intestinal problems (9.9% and 8.7%), tiredness/fatigue (8.8% and 8.7%), fever (5.5% and 8.7%), and skin problems (4.4% and 8.7%).

According to the myeloma patients who responded to this question, sexual problems constitute the most frequent treatment-related side effect that they don't feel comfortable reporting to their doctor (32.4%), followed by diarrhea/constipation/gastro-intestinal problems and psychological problems (23.5% each), neurological problems and anxiety/depression (17.7% each), and tiredness/fatigue (14.7%). Other side effects not or rarely reported to the doctor include fever, skin problems, and pain (11.8% each), nausea/vomiting (8.8%), body shakes, bladder aches, and family problems (2.9% each).

Of the patient relatives and caregivers who answered this question, almost one-quarter (23.08%) stated jaw problems as a treatment-related side effect that patients don't feel comfortable reporting to their doctor. Other side effects mentioned by patient relatives and caregivers in this context included tiredness/fatigue (15.4%), anxiety/depression, pain, psychological problems, frequent infections, and breathing difficulties (all 7.7%).

Graphs illustrating the differences between myeloma patients, patient relatives and caregivers from Poland and myeloma patients, patient relatives and caregivers from other countries are shown in the “Additional Graphs” section at the end of this report.



Graph 11) Treatment side effects not or rarely reported (in %)

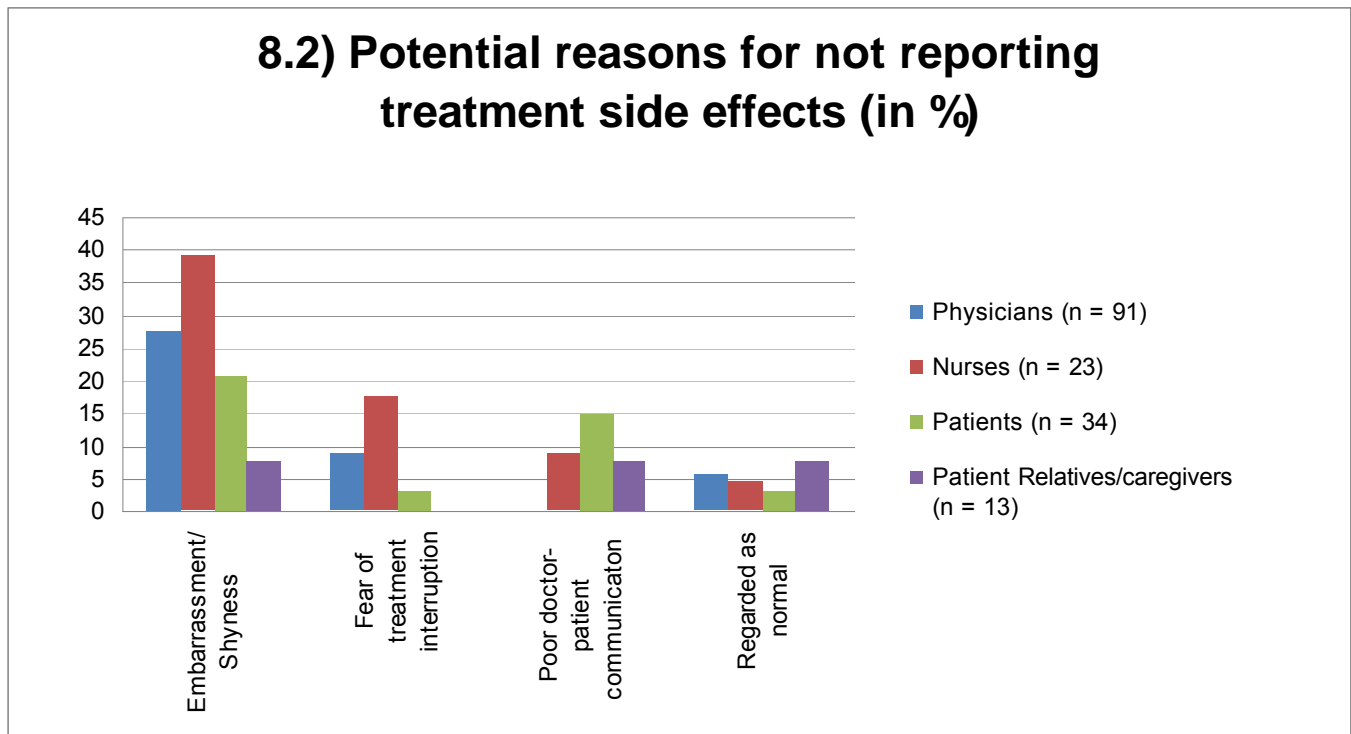
## Question 8.2) Potential reasons for not reporting treatment side effects

When asked about the potential reasons for not reporting treatment-related side effects, more than one-quarter of the physicians (27.5%), more than one-third of the nurses (39.1%), more than one-fifth (20.6%) of the patients and close to one in ten patient relatives and caregivers (7.7%) who responded to this question stated that it was because of embarrassment/shyness.

The assumption of several physicians (8.8%) and nurses (17.4%) that patients might not report side effects out of fear that their treatment might have to be interrupted as a result was not confirmed by the answers given by myeloma patients. However, about one in seven patients (14.7%) and about one in ten nurses (8.7%) and patient relatives and caregivers (7.7%) considered poor doctor-patient communication to be a potential reason for not reporting treatment-related side effects. This potential reason was not mentioned by any of the physicians who responded to this question.

Regarding treatment side effects as “normal” (i.e. as a normal part of treatment) was stated as another potential reason for not reporting treatment side effects by some of the participants who answered this question (5.5% of physicians, 4.4% of nurses, 2.9% of patients, and 7.7% of patient relatives and caregivers).

Graphs illustrating the differences between myeloma patients, patient relatives and caregivers from Poland and myeloma patients, patient relatives and caregivers from other countries are shown in the “Additional Graphs” section at the end of this report.



Graph 12) Potential reasons for not reporting treatment side effects (in %)

### Question 9:

“Appropriate management of treatment-related side effects is one of many important aspects of myeloma treatment and care. How would you rate your experience with regards to:”

- 1) = Management of treatment side effects; 2) = Patient access to information and support;  
 3) = Access to novel treatments; 4) = Coverage of treatment costs; 5) = Overall quality of treatment and care;  
 6) = Psycho-social support offered; 7) = Emotional support offered

1) = Very satisfied; 2) = Fairly well satisfied; 3) = Satisfied; 4) Not too satisfied; 5) Not satisfied at all

### **Question 9.1) Management of treatment side effects**

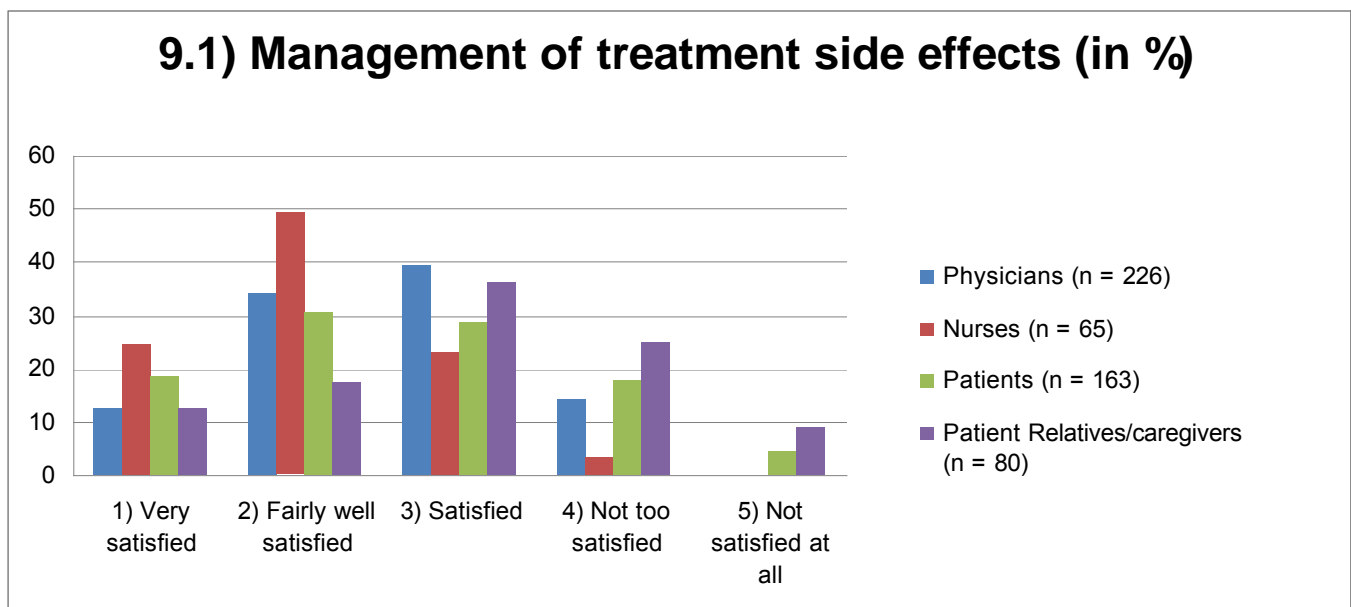
Of the physicians who responded to this first out of seven general question about myeloma treatment and care, less than half were “very satisfied” (12.4%) or “fairly well satisfied” (34.1%) with the management of treatment side effects, while more than 50% were “satisfied” (39.4%) or “not too satisfied” (14.2%) with the management of the side effects of myeloma treatment.

The nurses who answered this question had a better opinion of the management of treatment side effects: About one-quarter of them (24.6%) were “very satisfied,” about half of them (49.2%) were “fairly well satisfied,” and about another quarter of them (26.2%) were either “satisfied” or “not too satisfied” with how myeloma treatment side effects are managed.

About half of the patients who responded to this question (49.1%) were either “very satisfied” or “fairly well satisfied” with the management of treatment side effects, about one-quarter (28.9%) were “satisfied,” and more than one in five patients (22.1%) was either “not too satisfied” or “not satisfied at all” with the way treatment side effects are managed.

The level of dissatisfaction with the management of treatment side effects was even higher with the patient relatives and caregivers who answered this question: About one-third of them (30%) were either “very satisfied” or “fairly well satisfied,” another third (36.3%) were “satisfied,” and the final third (33.8%) were either “not too satisfied” or “not satisfied at all” with how myeloma treatment side effects are managed.

Graphs illustrating the differences between myeloma patients, patient relatives and caregivers from Poland and myeloma patients, patient relatives and caregivers from other countries are shown in the “Additional Graphs” section at the end of this report.



Graph 13) Management of treatment side effects (in %)

### **Question 9.2) Patient access to information and support**

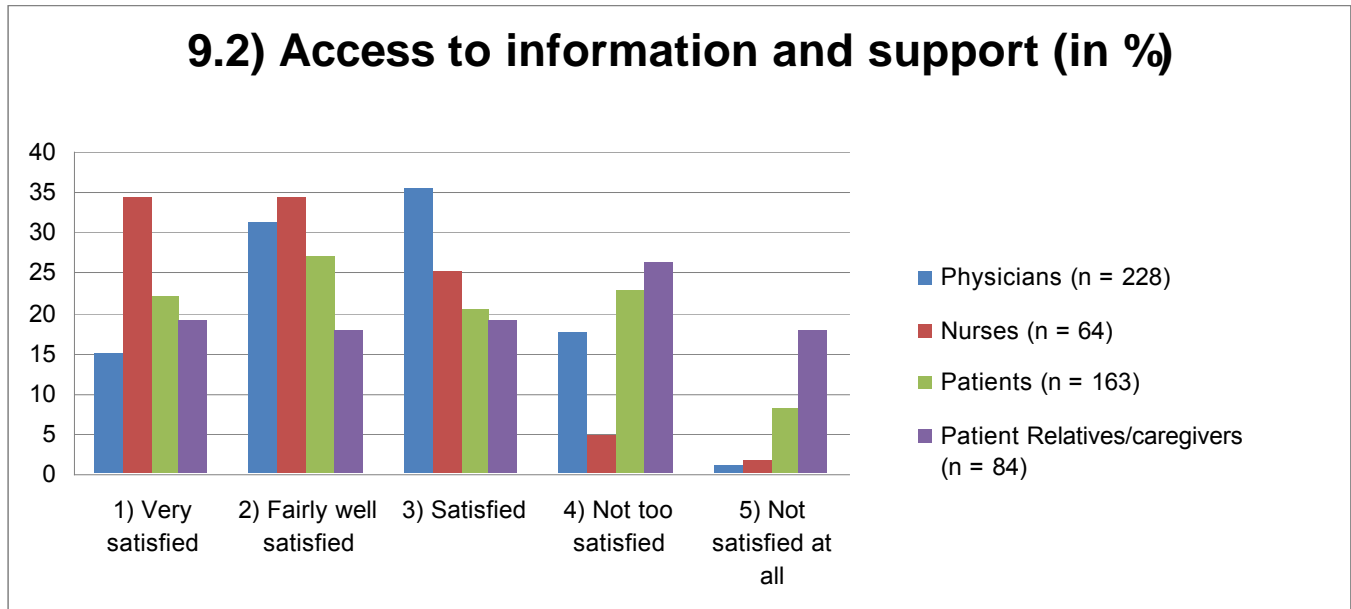
When asked about their satisfaction regarding patient access to information and support, less than one half of the physicians who answered this question (46.1%) stated that they were either “very satisfied” or “fairly well satisfied,” about one-third said that they were “satisfied,” and about one in five physicians (18.4%) stated that they were either “not too satisfied” or “not satisfied at all” with patient access to information and support.

More than two-thirds of the nurses who responded to this question (68.8%) were either “very satisfied” or “fairly well satisfied” with the access of patients to information and support, one-quarter of them (25%) were “satisfied” and only a small number of nurses (6.3%) were “not too satisfied” or “not satisfied at all.”

Of the myeloma patients who answered this question, about half (49.1%) stated that they were “very satisfied” or “fairly well satisfied” with patient access to information and support, about one-fifth (20.3%) were “satisfied” but around one-third of patients (30.7%) were “not too satisfied” or “not satisfied at all” regarding their access to information and support.

The patient relatives and caregivers who responded to this question were even more critical regarding the access of the myeloma patients they were representing in this survey to information and support: While only about one-fifth of them were either “very satisfied,” “fairly well satisfied” or “satisfied” (19.1%, 17.9% and 19.1% respectively), almost half of them (44.1%) stated that they were “not too satisfied” or “not satisfied at all.”

Graphs illustrating the differences between myeloma patients, patient relatives and caregivers from Poland and myeloma patients, patient relatives and caregivers from other countries are shown in the “Additional Graphs” section at the end of this report.



Graph 14) Patient access to information and support (in %)

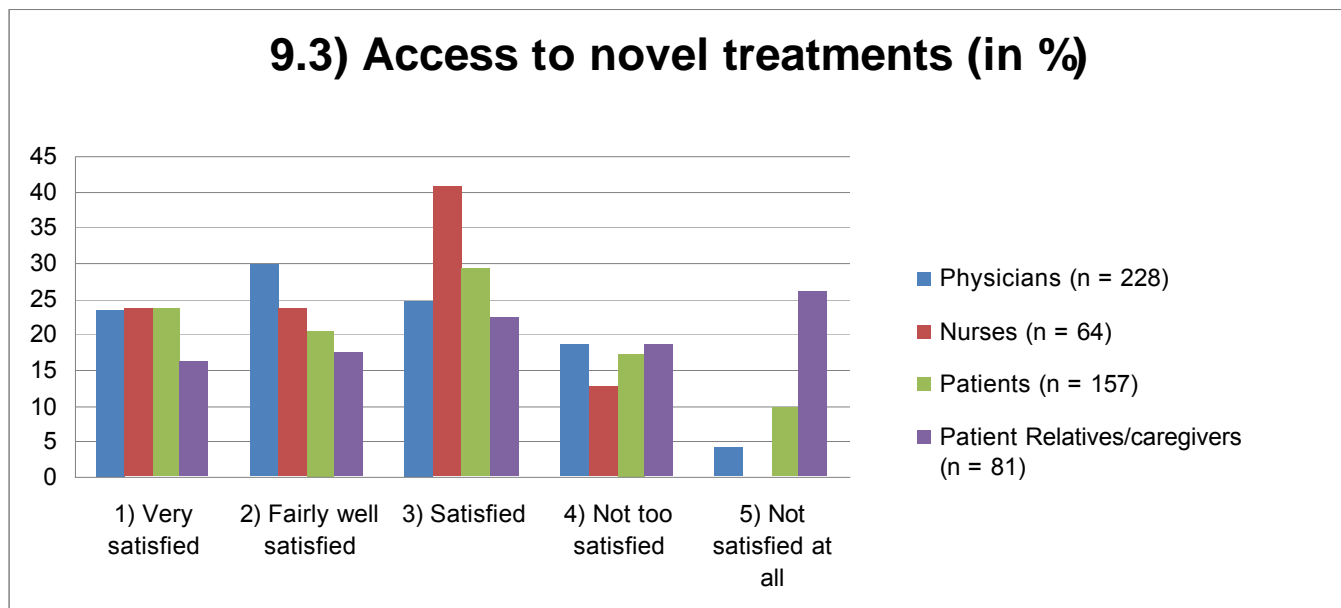
### **Question 9.3) Access to novel treatments**

According to the outcome of this survey, access to novel myeloma treatments appears to be an issue for both physician and patient communities: While only about one in ten nurses (12.5%) who responded to this survey question was “not too satisfied” with access to novel treatments, more than one-fifth of physicians (22.4%), more than one-quarter of patients (26.8%) and almost half of the patient relatives and caregivers (44.5%) responded that they were either “not too satisfied” or “not satisfied at all” with access to novel treatments.

However, about one-quarter of the physicians, nurses and myeloma patients who answered this question (23.3%, 23.4% and 23.6% respectively) said that they were “very satisfied” with access to novel treatments.

Graphs illustrating the differences between myeloma patients, patient relatives and caregivers from Poland and myeloma patients, patient relatives and caregivers from other countries are shown in the “Additional Graphs” section at the end of this report.

### 9.3) Access to novel treatments (in %)



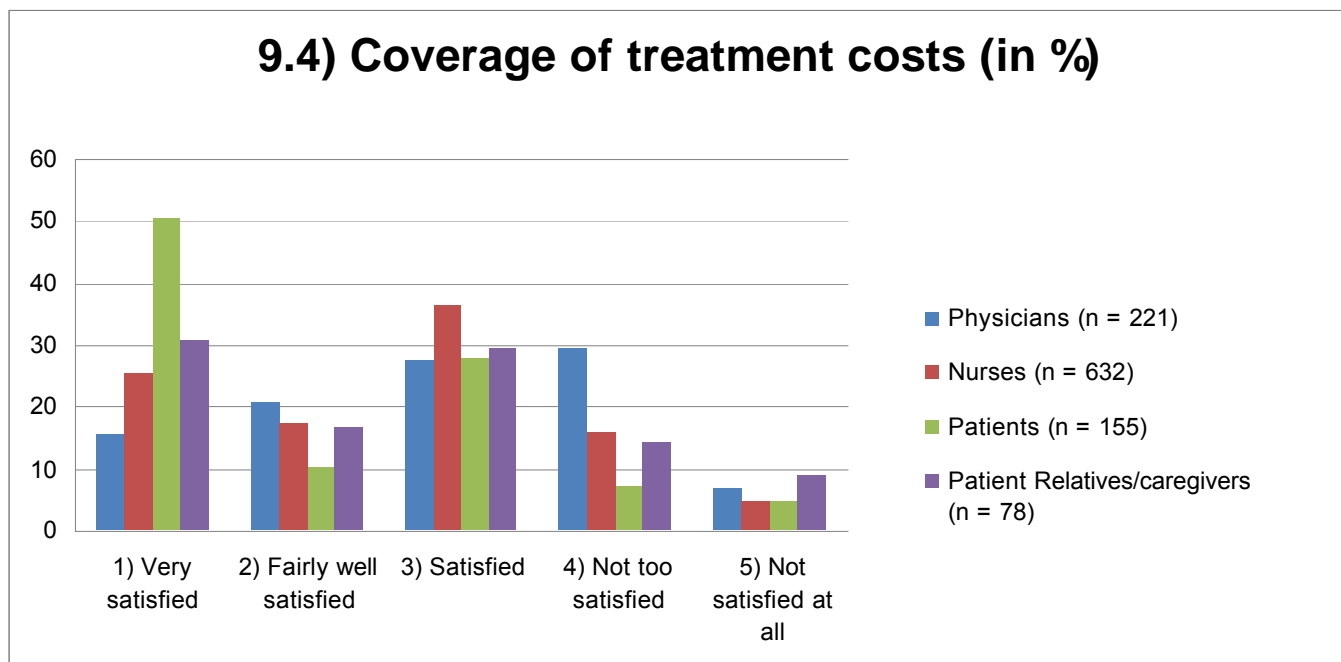
Graph 15) Access to novel treatments (in %)

### Question 9.4) Coverage of treatment costs

While almost two-thirds of the myeloma patients (60.6%) and close to half of the patient relatives and caregivers who responded to this question (47.4%) stated that they were “very satisfied” or “fairly well satisfied” concerning the coverage of myeloma treatment costs, more than one-third of the physicians (36.2%), one-fifth of the nurses (20.6%) and about one-quarter of the patient relatives and caregivers (23.1%) who answered this question said that they were “not too satisfied” or “not satisfied at all” with the coverage of treatment costs.

Graphs illustrating the differences between myeloma patients, patient relatives and caregivers from Poland and myeloma patients, patient relatives and caregivers from other countries are shown in the “Additional Graphs” section at the end of this report.

### 9.4) Coverage of treatment costs (in %)



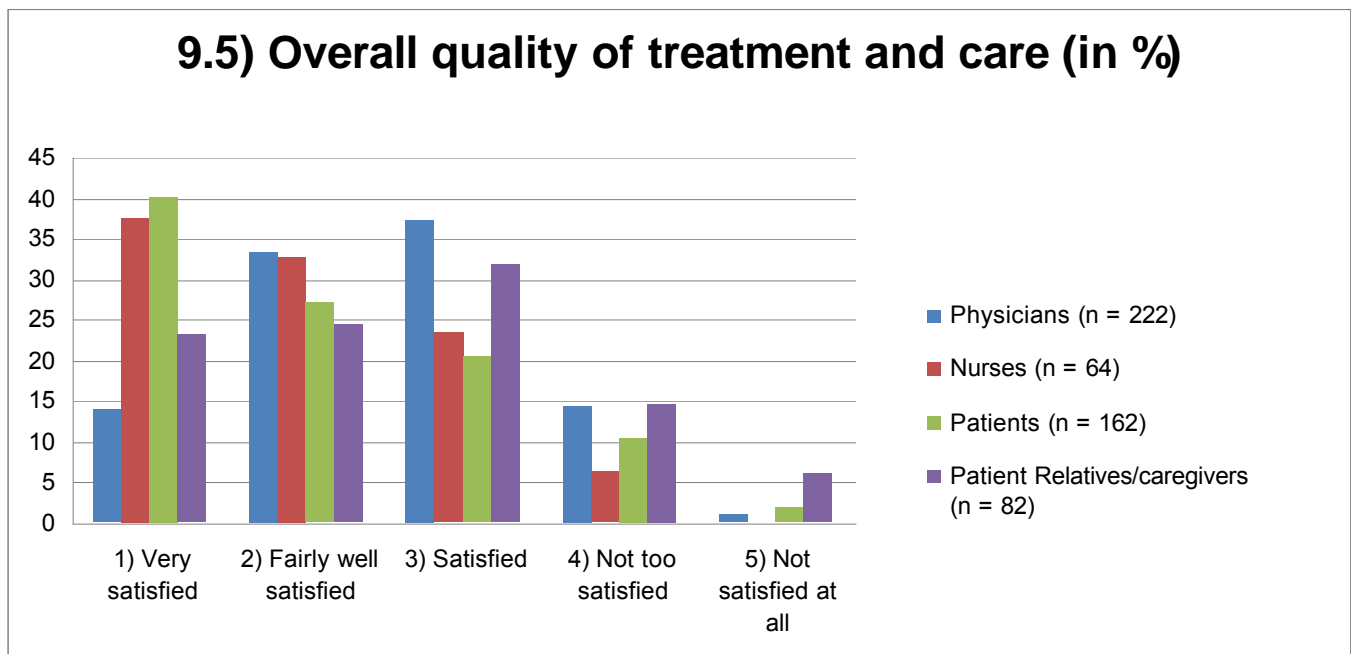
Graph 16) Coverage of treatment costs (in %)

### **Question 9.5) Overall quality of treatment and care**

When asked about how satisfied they were regarding the overall quality of myeloma treatment and care, almost half of the physicians (47.3%), more than two-thirds of the nurses (70.3%) and patients (67.3%), and almost half of the patient relatives and caregivers (47.6%) who have answered this question stated that they were either “very satisfied” or “fairly well satisfied” with the overall quality of treatment and care provided for myeloma patients.

However, about 15% of the physicians (15.3%), more than one in ten of the patients (12.3%) and more than one in five of the patient relatives and caregivers (20.7%) who responded to this question stated that they were either “not too satisfied” or “not satisfied at all” with the quality of myeloma treatment and care.

Graphs illustrating the differences between myeloma patients, patient relatives and caregivers from Poland and myeloma patients, patient relatives and caregivers from other countries are shown in the “Additional Graphs” section at the end of this report.



Graph 17) Overall quality of treatment and care (in %)

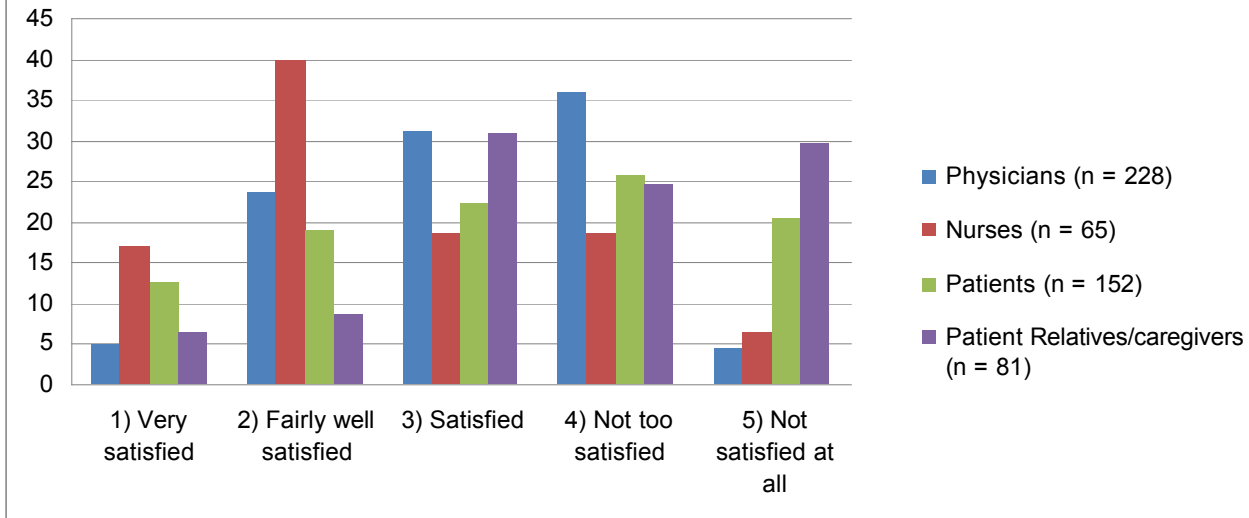
### **Question 9.6) Psycho-social support offered**

According to the answers received in response to this survey, psycho-social support for people affected by myeloma is an area that leaves a lot to be desired: More than one-third of the physicians (40.4%), almost one-quarter of the nurses (24.6%), almost half of the patients (46.1%), and more than half of the patient relatives and caregivers (54.3%) who responded to this question said that they were either “not too satisfied” or “not satisfied at all” with the psycho-social support offered.

The only group of participants of which more than half (56.9%) stated that they were “very satisfied” or “fairly well satisfied” with this kind of support were the nurses. Of the physicians who responded to this question, less than one-third (28.5%) stated that they were “very satisfied” or “fairly well satisfied” with the psycho-social support offered to those affected by myeloma.

Graphs illustrating the differences between myeloma patients, patient relatives and caregivers from Poland and myeloma patients, patient relatives and caregivers from other countries are shown in the “Additional Graphs” section at the end of this report.

## 9.6) Psycho-social support offered (in %)



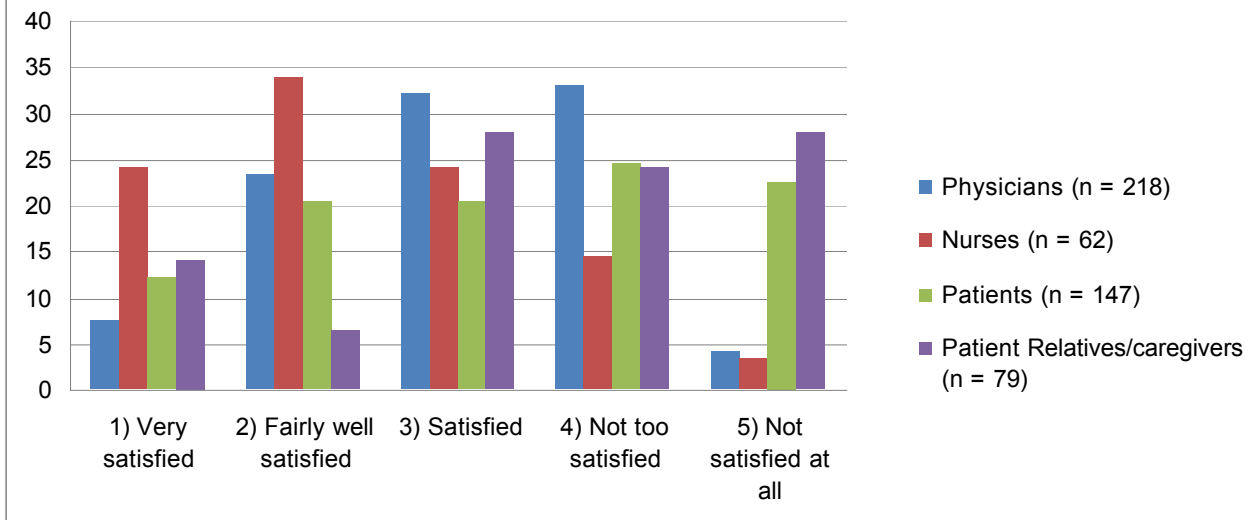
Graph 18) Psycho-social support offered (in %)

### **Question 9.7) Emotional support offered**

As with psycho-social support, the nurses who responded to this question were the only group of which more than half (58.1%) stated that they were “very satisfied” or “fairly well satisfied” with the emotional support offered to people affected by myeloma. Correspondingly, only about one in five nurses (17.8%) said that they were “not too satisfied” or “not satisfied at all” with the emotional support offered. This, however, was stated by more than one-third of the physicians (37.2%), almost half of the patients (46.9%) and more than half of the patient relatives and caregivers (51.9%) who responded to this question.

Graphs illustrating the differences between myeloma patients, patient relatives and caregivers from Poland and myeloma patients, patient relatives and caregivers from other countries are shown in the “Additional Graphs” section at the end of this report.

## 9.7) Emotional support offered (in %)

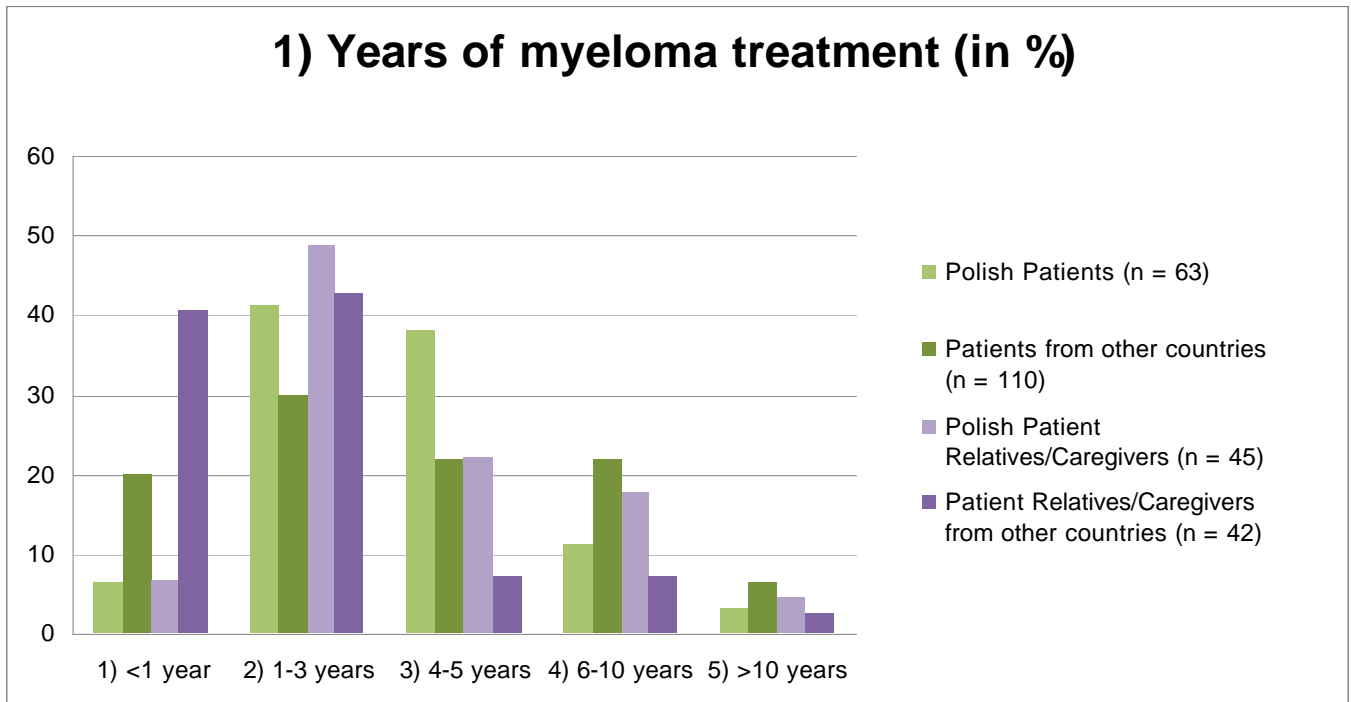


Graph 19) Emotional support offered (in %)



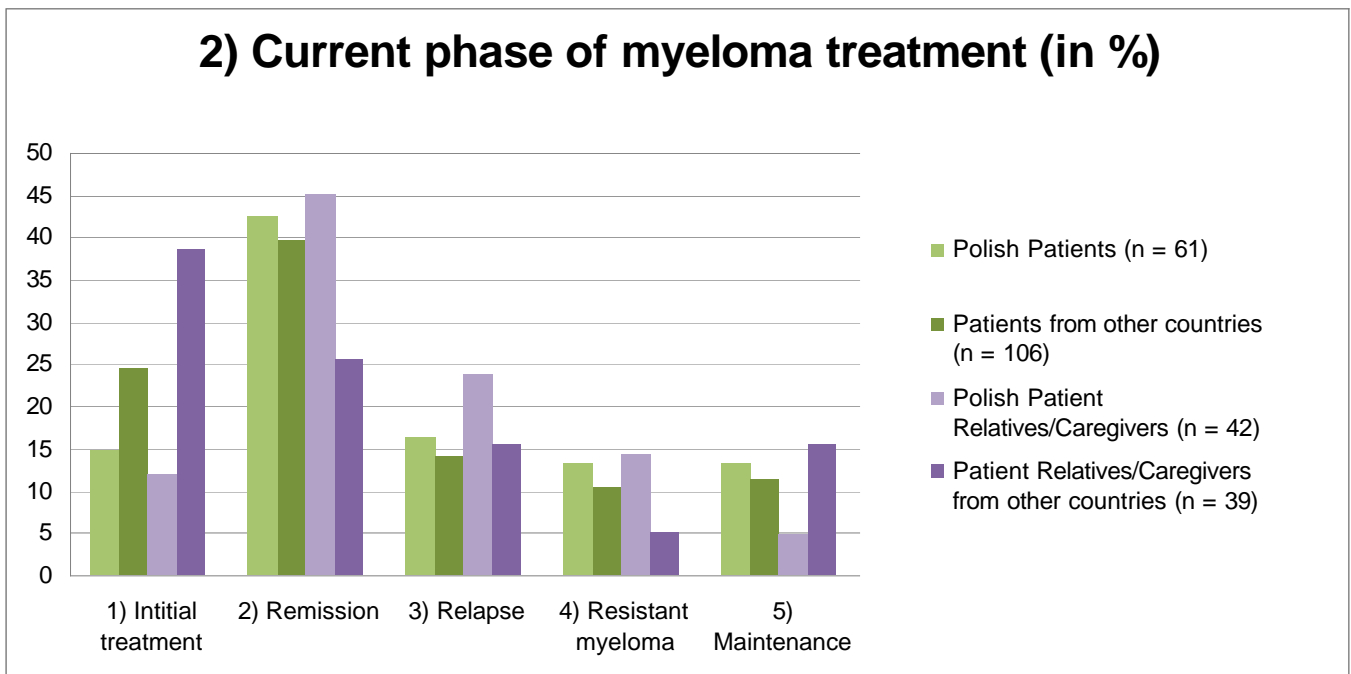
# Additional Graphs

## Question 1 for patients/patient relatives/caregivers



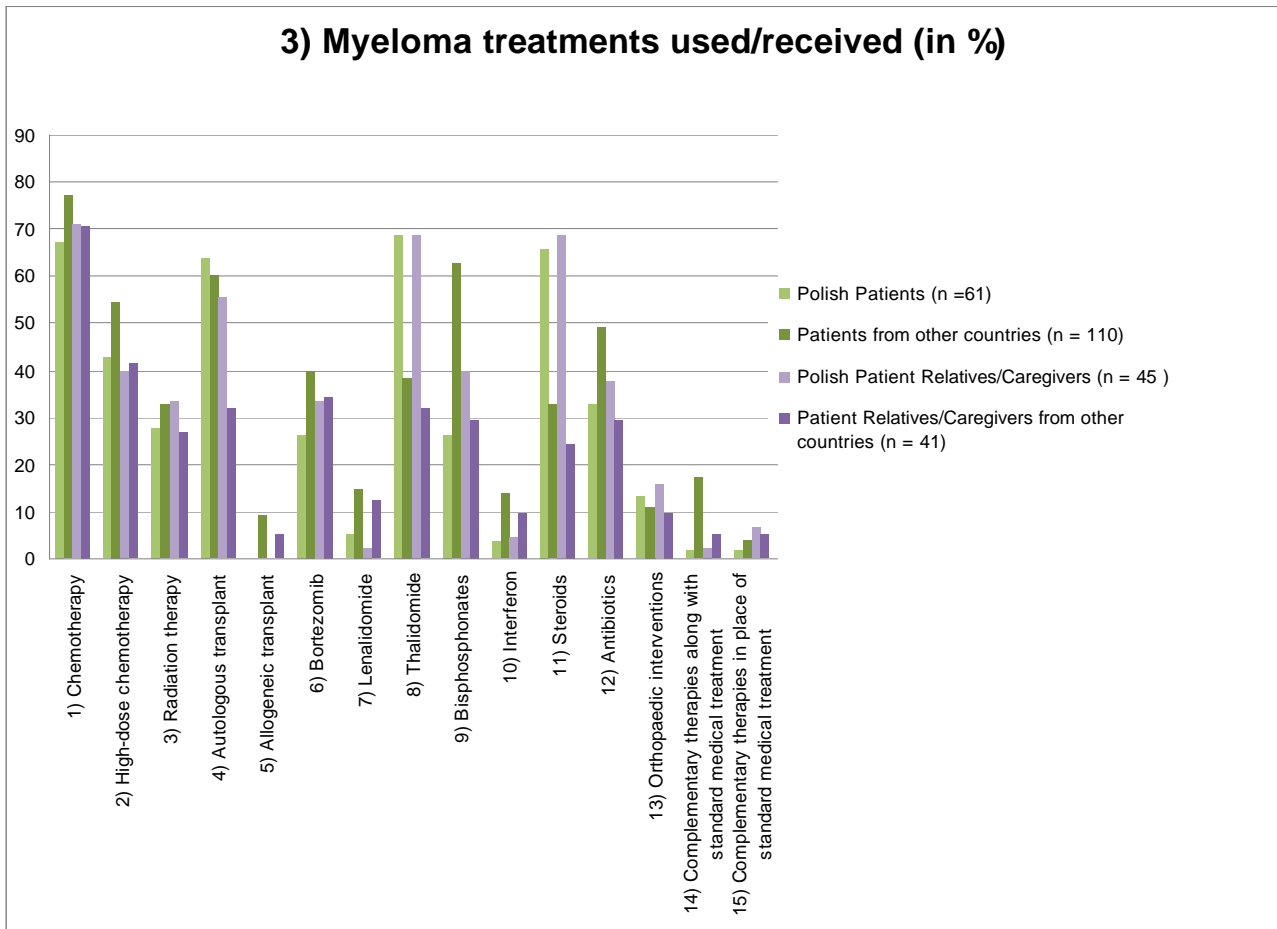
Graph 3a) Years of myeloma treatment as indicated by Polish patients, patient relatives and caregivers and patients, patient relatives and caregivers from other countries (in %)

## Question 2 for patients/patient relatives/caregivers



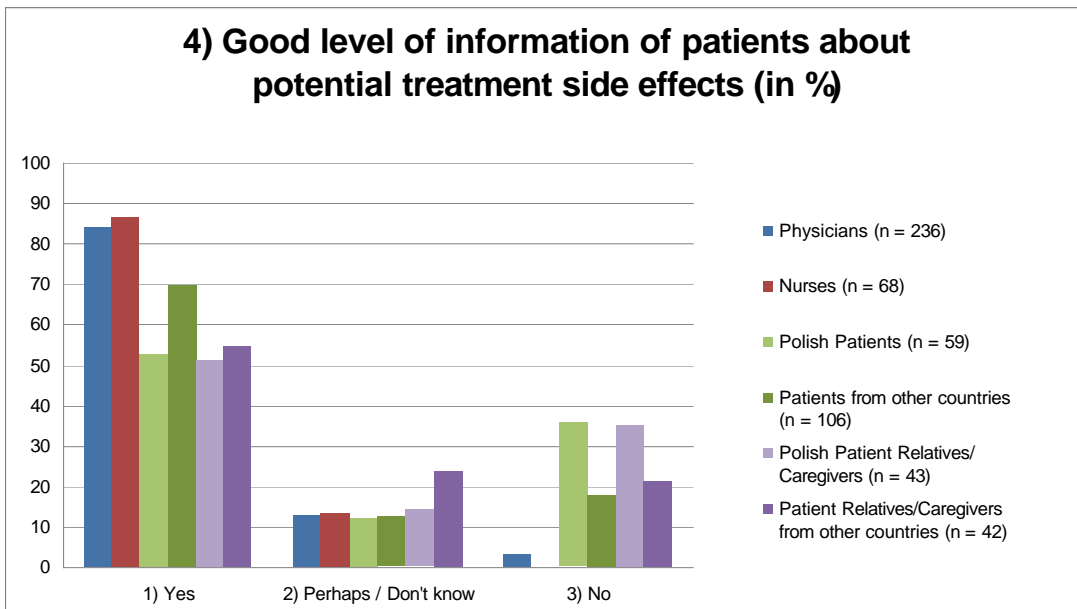
Graph 4a) Current phase of myeloma treatment as indicated by Polish patients, patient relatives and caregivers and patients, patient relatives and caregivers from other countries (in %)

**Question 3 for patients/patient relatives/caregivers**



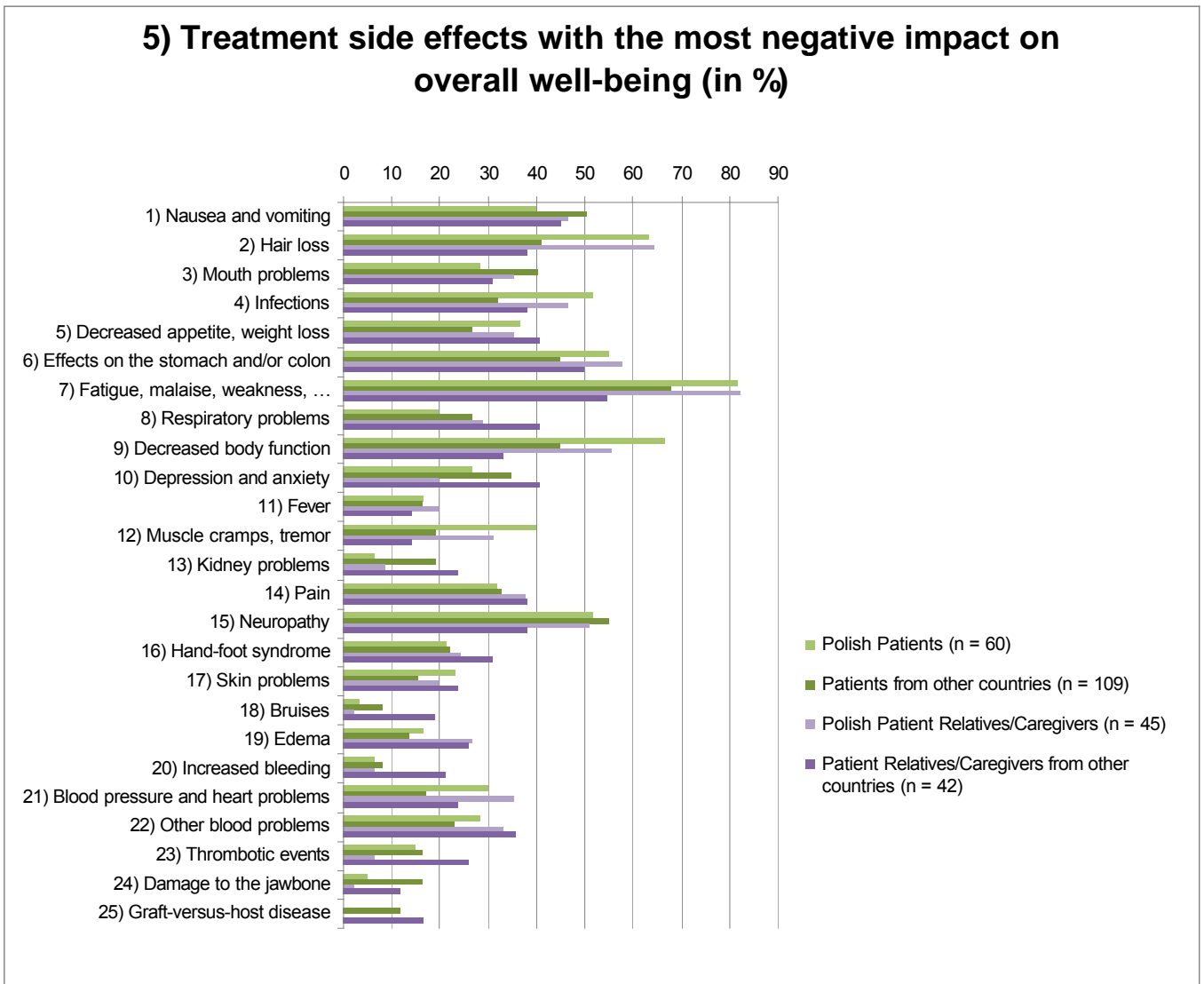
Graph 5a) Myeloma treatments received as indicated by Polish patients, patient relatives and caregivers and patients, patient relatives and caregivers from other countries (in %)

**Question 4 for physicians/nurses/patients/patient relatives/caregivers**



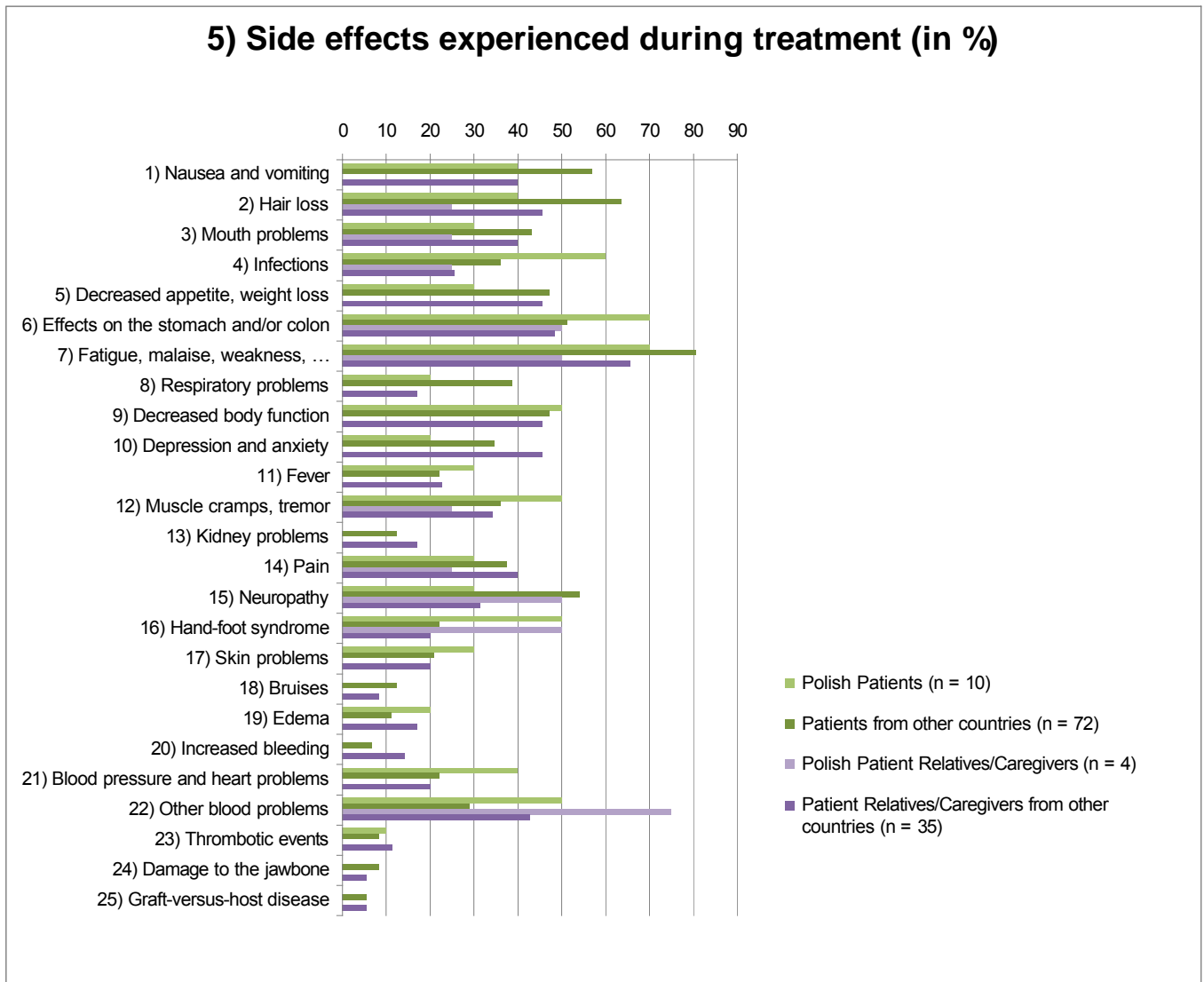
Graph 6a) Good level of information of patients about potential myeloma treatment side effects as indicated by physicians, nurses, Polish patients, patient relatives and caregivers and patients, patient relatives and caregivers from other countries (in %)

**Question 5 for patients/patient relatives/caregivers**



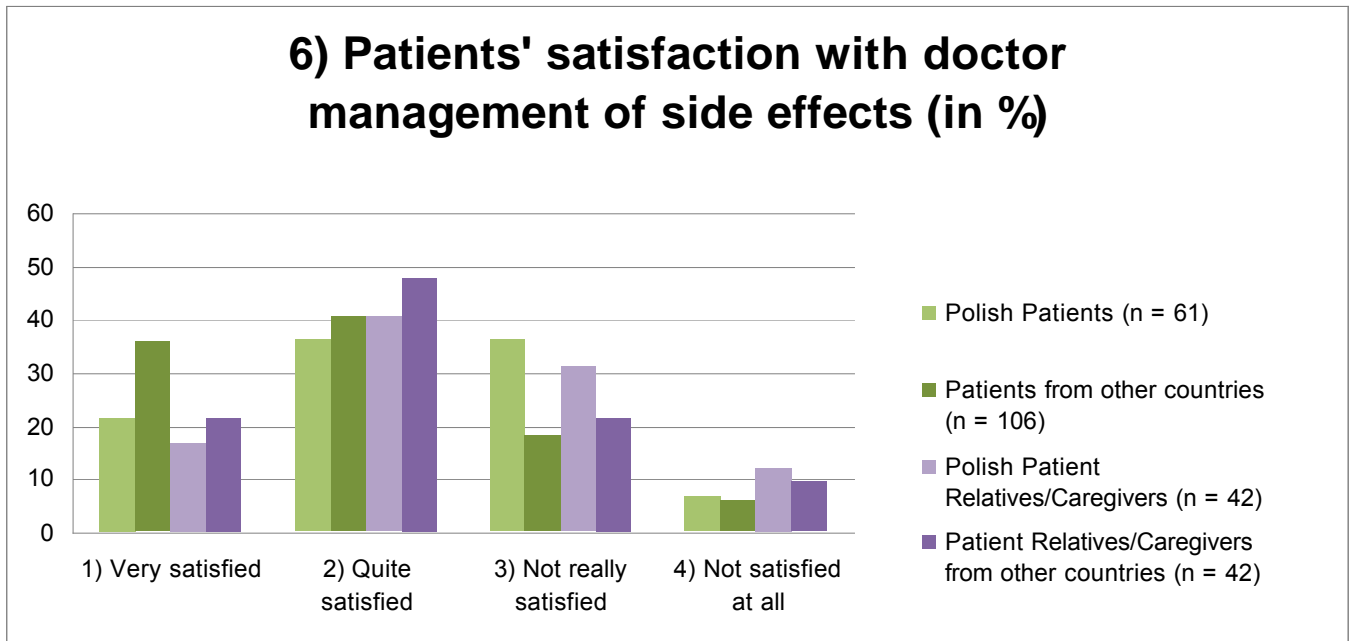
Graph 7a) Myeloma treatment side effects with the most negative impact on overall well-being as indicated by Polish patients, patient relatives and caregivers and patients, patient relatives and caregivers from other countries (in %)

**Question 5 for patients/patient relatives/caregivers**



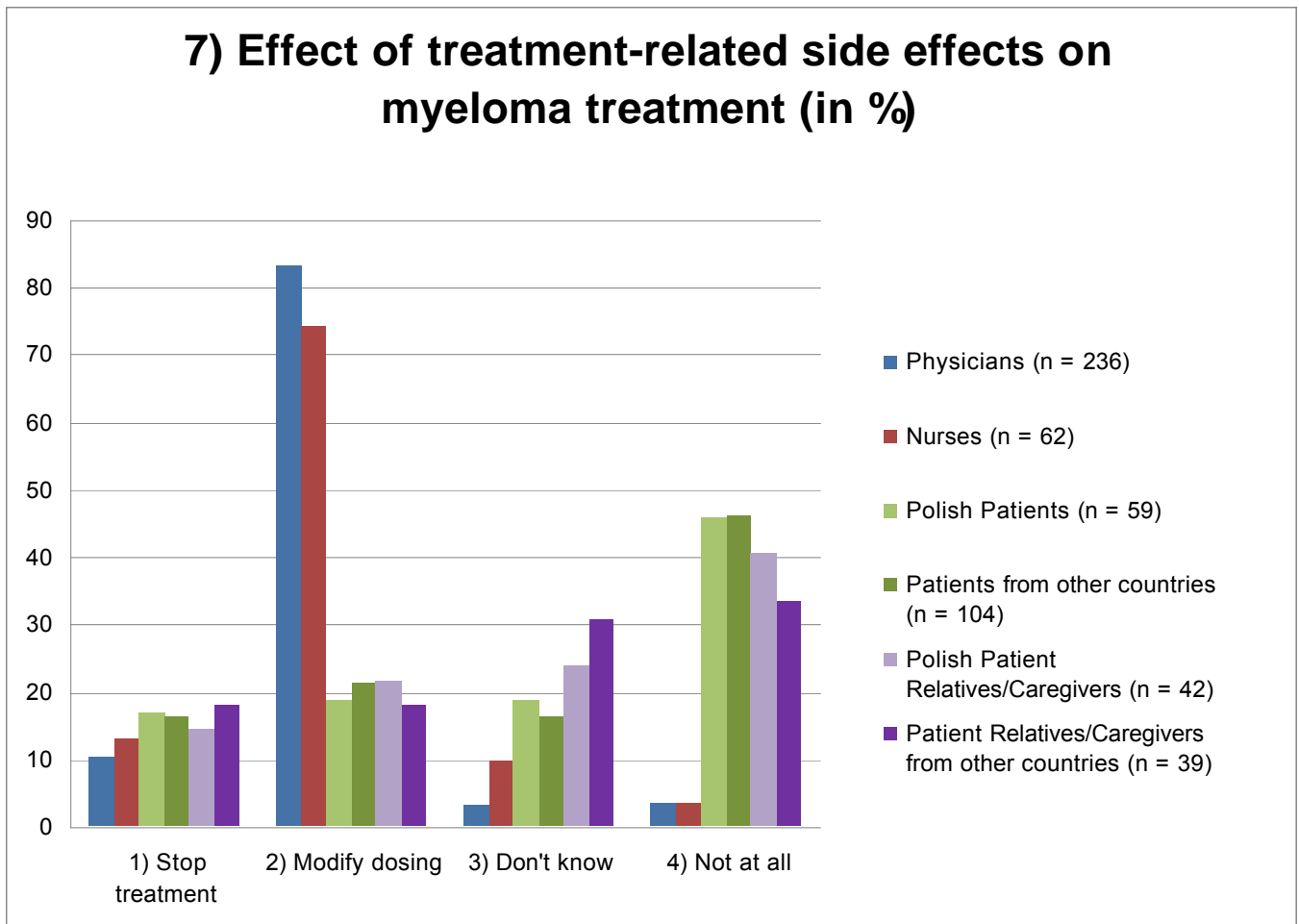
Graph 8a) Side effects experienced during myeloma treatment as indicated by Polish patients, patient relatives and caregivers and patients, patient relatives and caregivers from other countries (in %)

**Question 6 for patients/patient relatives/caregivers**



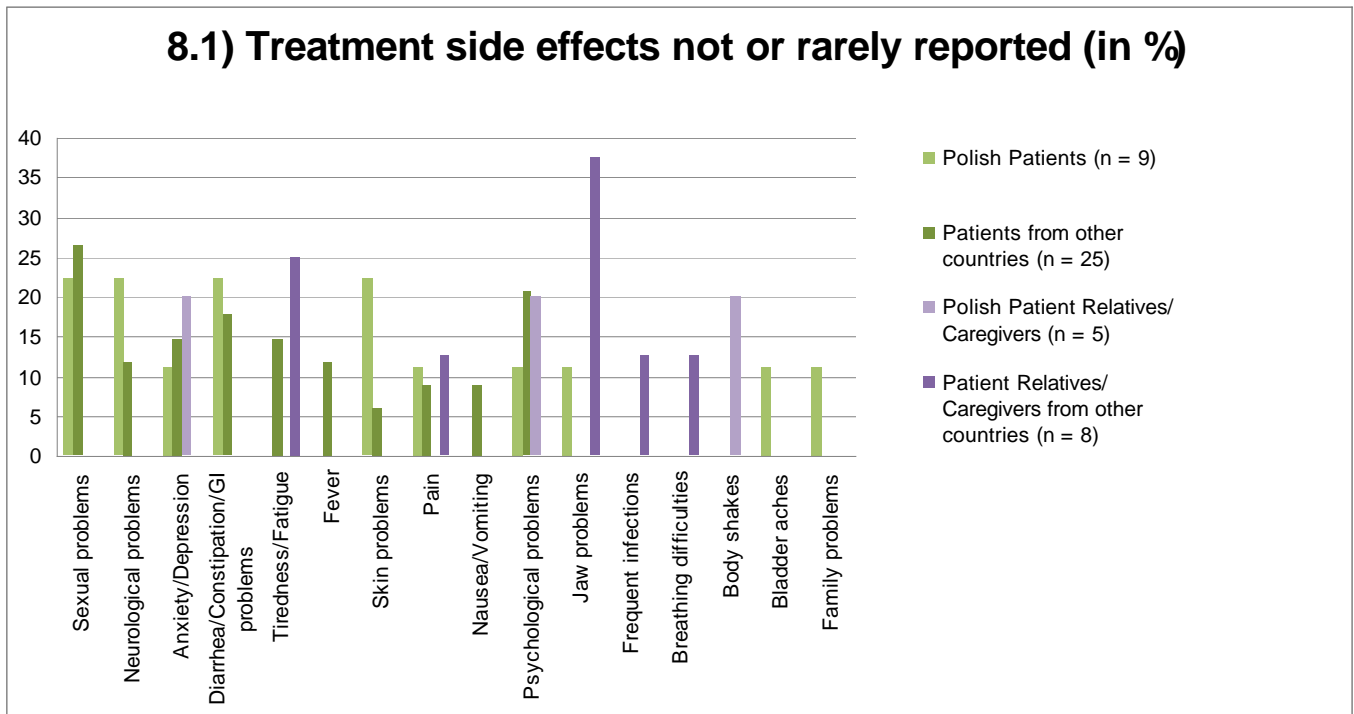
Graph 9a) Patients' satisfaction with doctor management of side effects as indicated by Polish patients, patient relatives and caregivers and patients, patient relatives and caregivers from other countries (in %)

**Question 7 for physicians/nurses/patients/patient relatives/caregivers**



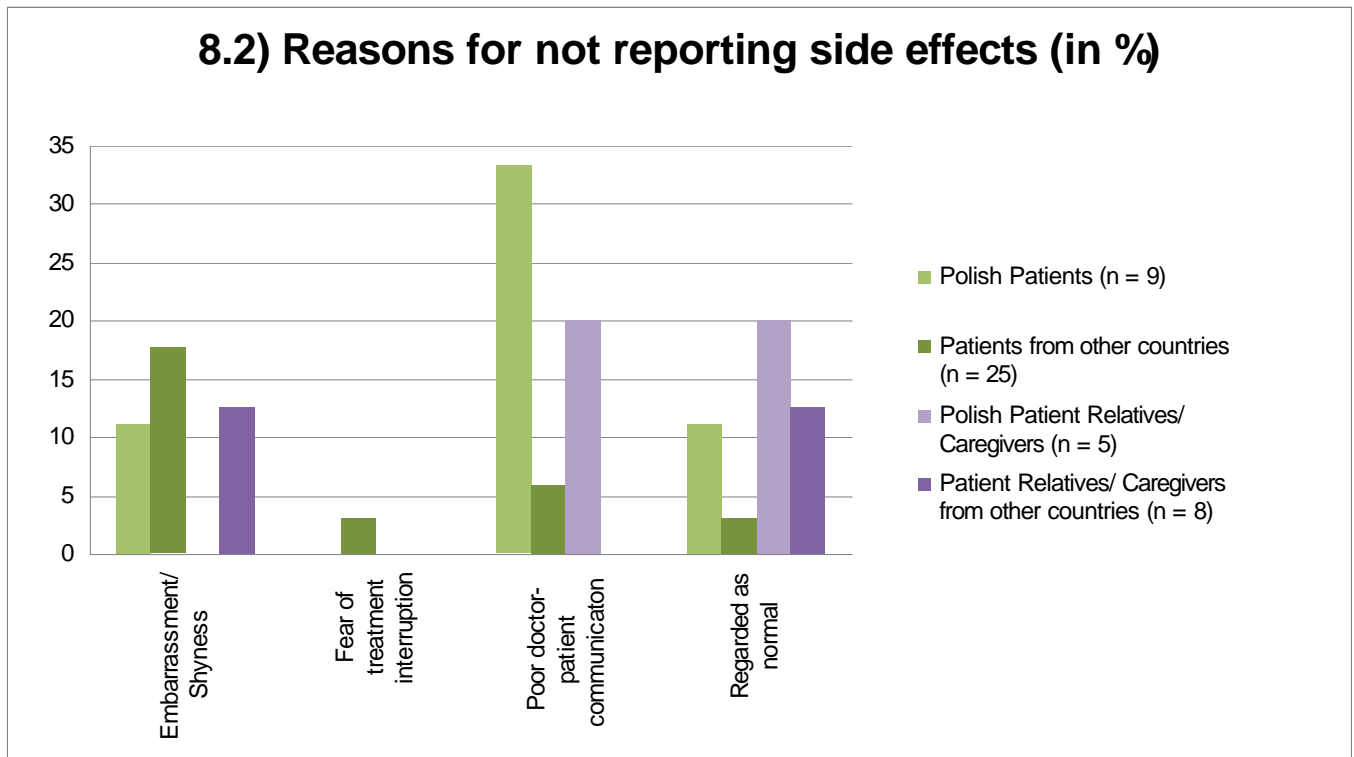
Graph 10a) Effect of treatment-related side effects on myeloma treatment as indicated by physicians, nurses, Polish patients, patient relatives and caregivers and patients, patient relatives and caregivers from other countries (in %)

**Question 8.1) for patients/patient relatives/caregivers**



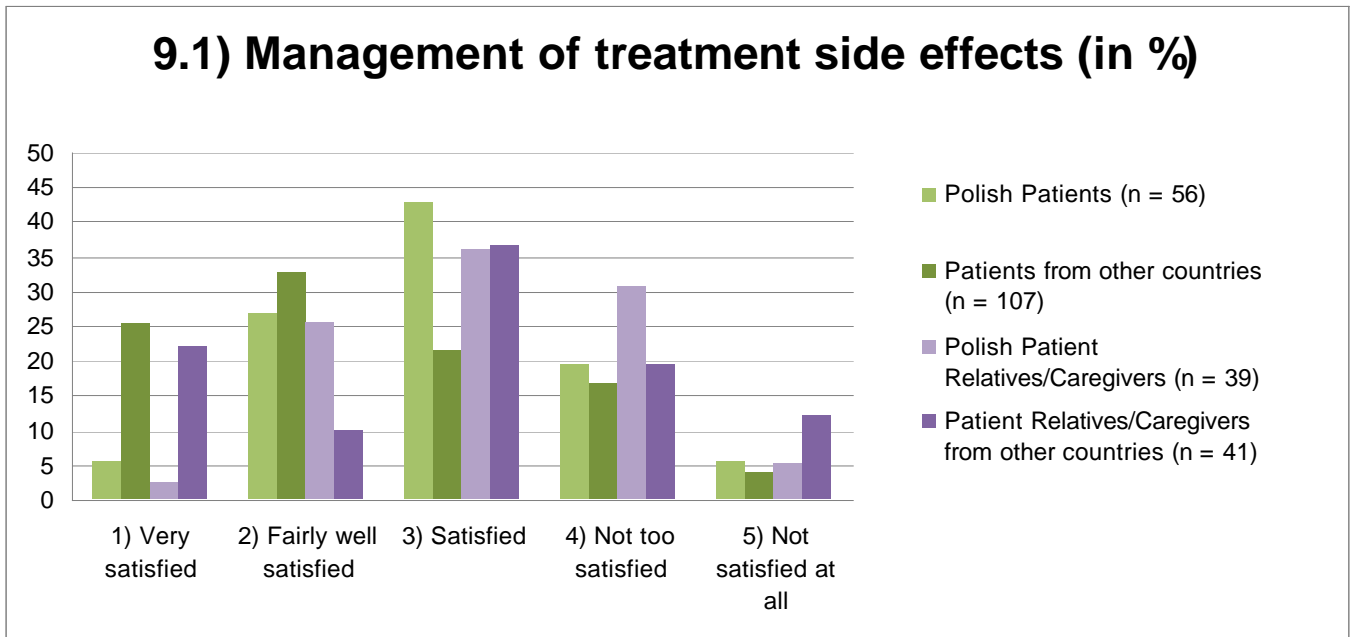
Graph 11a) Treatment side effects not or rarely reported as indicated by Polish patients, patient relatives and caregivers and patients, patient relatives and caregivers from other countries (in %)

**Question 8.2) for patients/patient relatives/caregivers**



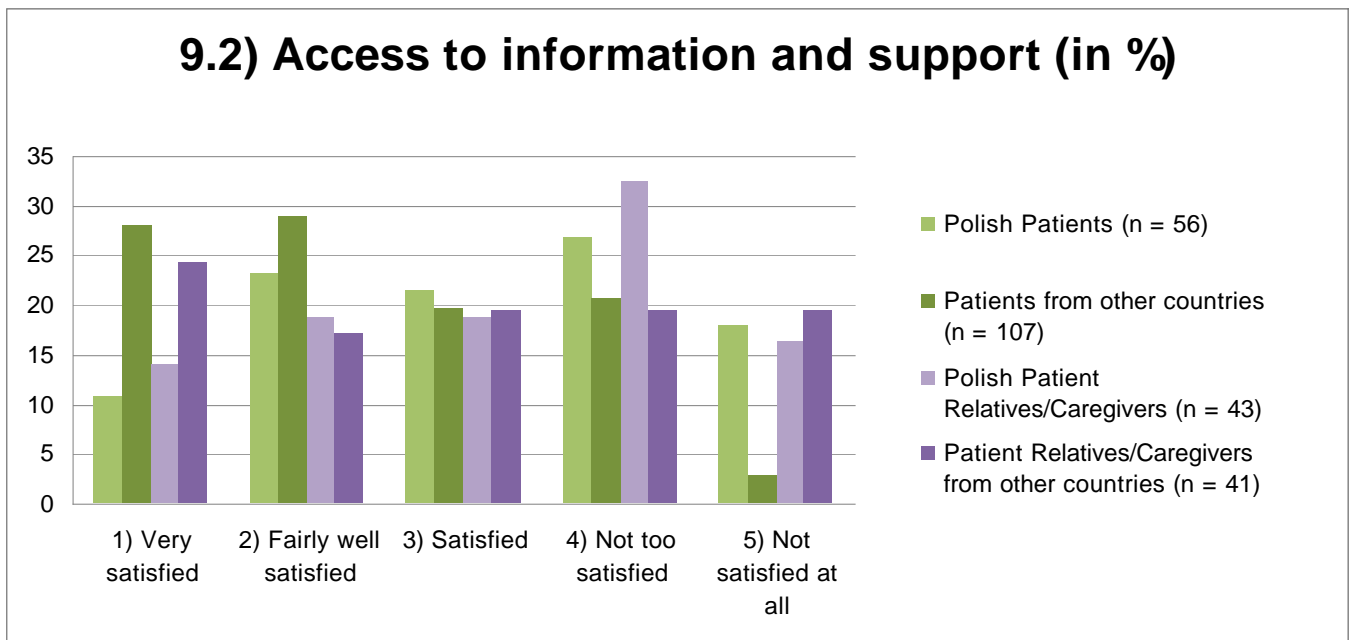
Graph 12a) Reasons for not reporting side effects as indicated by Polish patients, patient relatives and caregivers and patients, patient relatives and caregivers from other countries (in %)

**Question 9.1) for patients/patient relatives/caregivers**



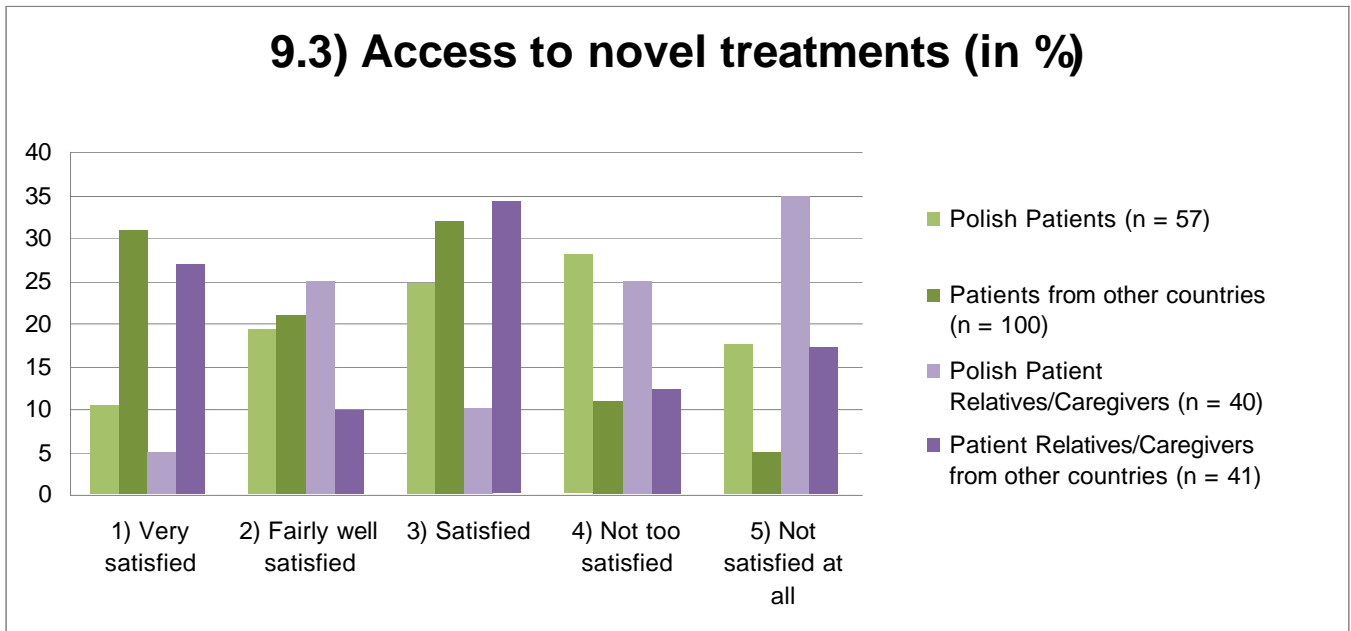
Graph 13a) Management of treatment side effects as indicated by Polish patients, patient relatives and caregivers and patients, patient relatives and caregivers from other countries (in %)

**Question 9.2) for patients/patient relatives/caregivers**



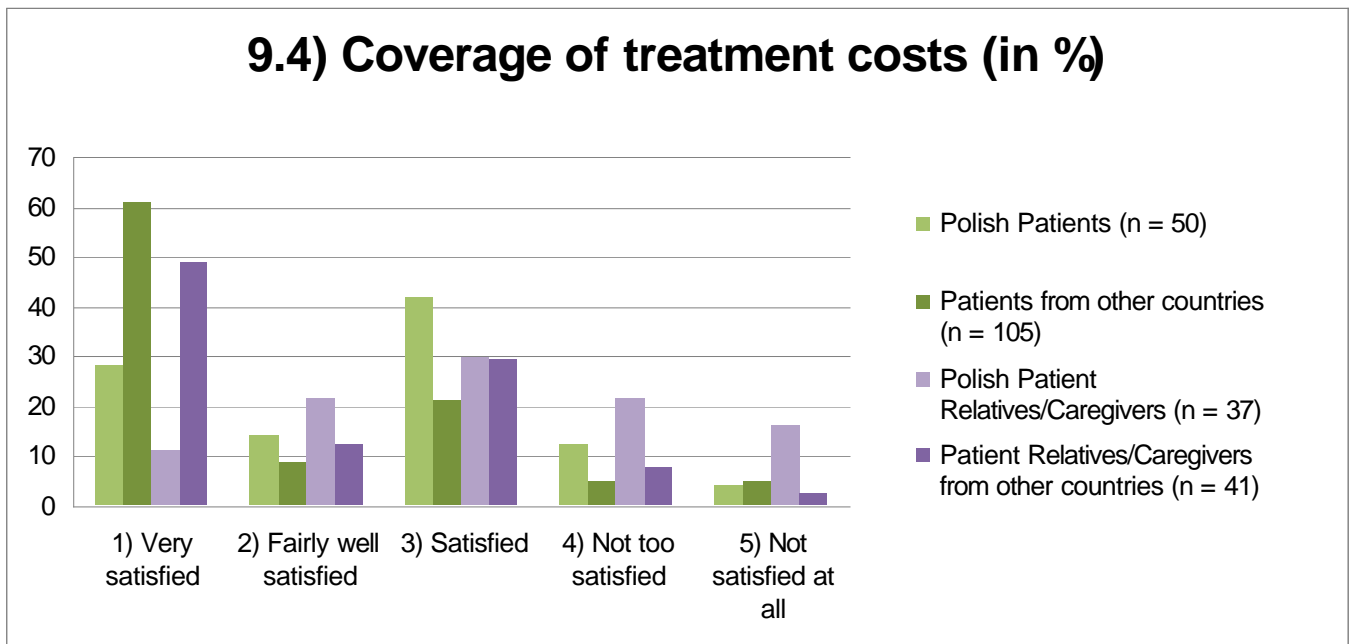
Graph 14a) Patient access to information and support as indicated by Polish patients, patient relatives and caregivers and patients, patient relatives and caregivers from other countries (in %)

**Question 9.3) for patients/patient relatives/caregivers**



Graph 15a) Access to novel treatments as indicated by Polish patients, patient relatives and caregivers and patients, patient relatives and caregivers from other countries (in %)

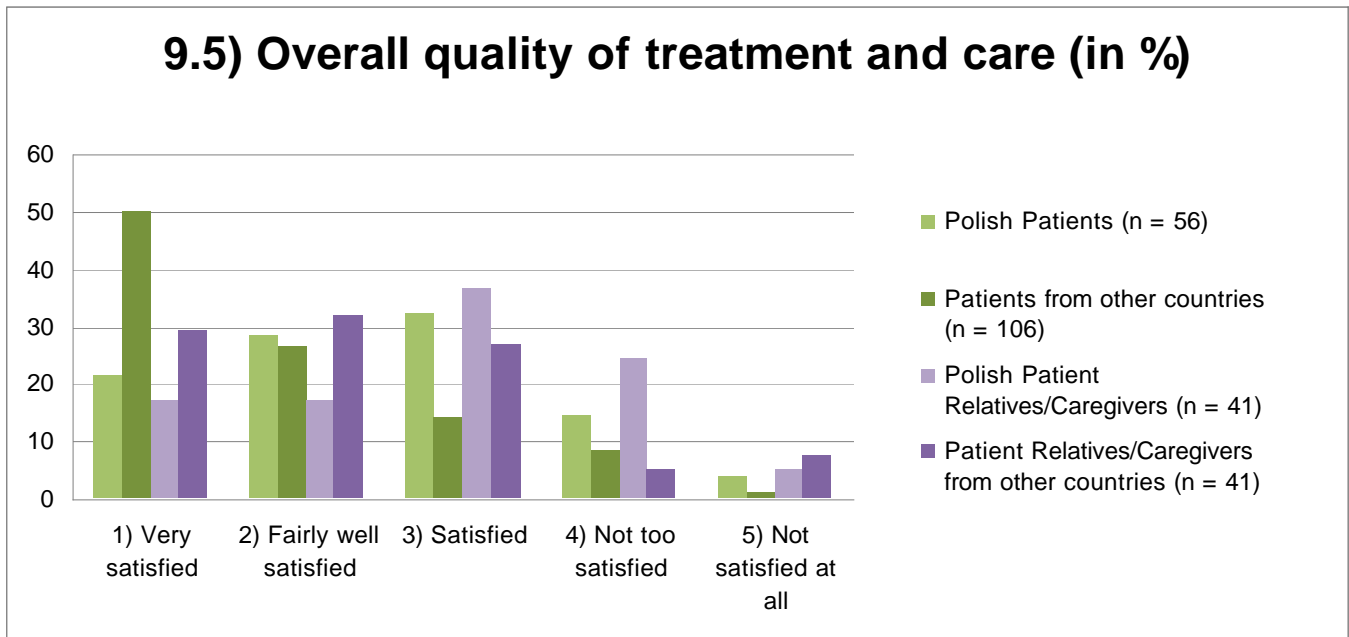
**Question 9.4) for patients/patient relatives/caregivers**



Graph 16a) Coverage of treatment costs as indicated by Polish patients, patient relatives and caregivers and patients, patient relatives and caregivers from other countries (in %)

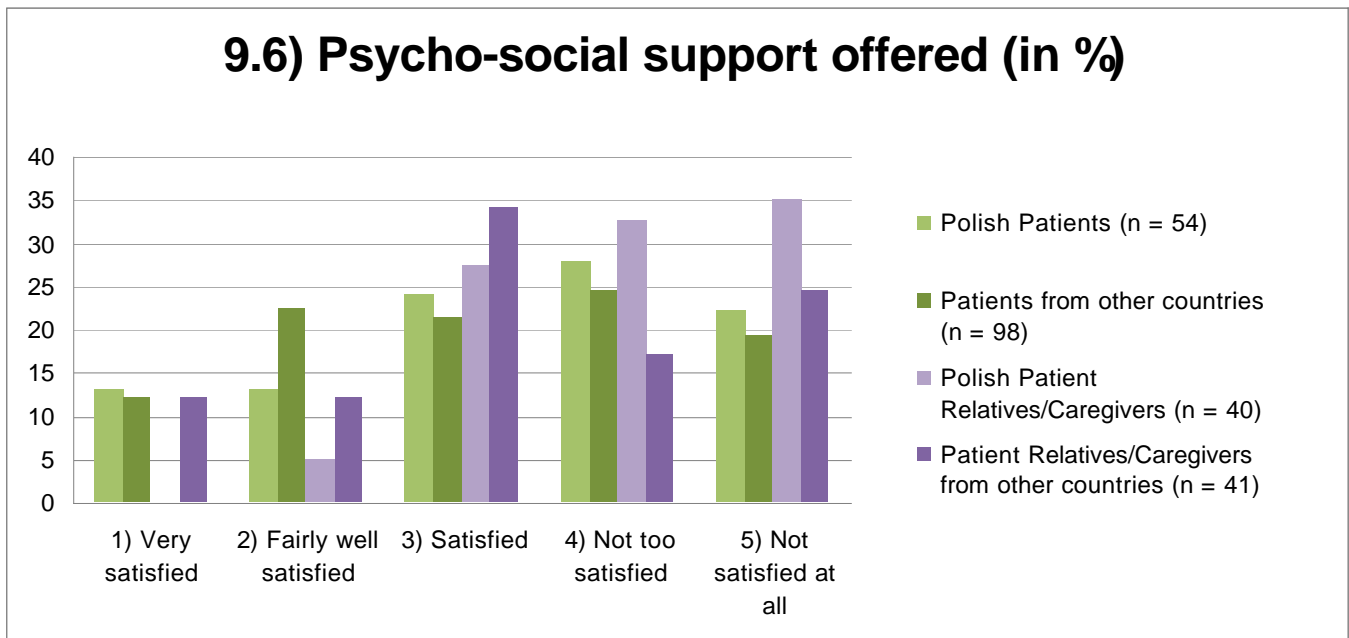


**Question 9.5) for patients/patient relatives/caregivers**



Graph 17a) Overall quality of treatment and care as indicated by Polish patients, patient relatives and caregivers and patients, patient relatives and caregivers from other countries (in %)

**Question 9.6) for patients/patient relatives/caregivers**



Graph 18a) Psycho-social support offered as indicated by Polish patients, patient relatives and caregivers and patients, patient relatives and caregivers from other countries (in %)

**Question 9.7) for patients/patient relatives/caregivers**



Graph 19a) Emotional support offered as indicated by Polish patients, patient relatives and caregivers and patients, patient relatives and caregivers from other countries (in %)