



MYELOMA  
EURONET

# Myeloma Euronet

## INTERNATIONAL SURVEY –

### MYELOMA TREATMENT COMPLIANCE 2009

## SUMMARY REPORT

*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 compliance, i.e. the correct following of a myeloma treatment plan. Survey results will be used to help encourage patient and medical communities as well as political decision-makers to focus greater attention on the issue of myeloma treatment compliance.

**Methods:** The survey was conducted between March and October 2009 during several international congresses, including 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), the 14th Congress of the European Hematology Association in Berlin, Germany (4-7 June 2009), the 15th Congress of the European CanCer Organisation and 34th Congress of the European Society for Medical Oncology in Berlin, Germany (20-24 September 2009), the Joint Annual Meeting of the Austrian, German and Swiss Societies for Haematology and Oncology in Mannheim, Germany (2-6 October 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) (27 April - 16 October 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, 278 healthcare professionals from 61 countries (195 or 70.1% from European countries) and 235 myeloma patients, patient relatives and caregivers from 13 countries of treatment (225 or 95.7% from European countries) have participated in the survey.

Healthcare professionals were subdivided into 196 physicians from 53 countries (108 haematologists (38.8%), 74 medical oncologists (26.6%), 14 haematologists-oncologists (5%), 17 radiation oncologists (6.1%), 7 surgical oncologists (2.5%), 76 nurses (27.3%) from 26 countries, and 6 other healthcare professionals (not included in the evaluation). Almost 95% of the physicians (94.4%) and more than 80% of the nurses (80.3%) were between 30 and 69 years of age. Of the physicians, 122 were male (62.2%) and 68 female (34.7%). Of the nurses, 7 were male (9.2%) and 66 female (86.8%). 6 physicians and 3 nurses did not indicate their gender.

Survey participants representing patient views were subdivided into 180 myeloma patients from 9 countries of treatment (76.6%) and 53 myeloma patient relatives (22.5%) and 2 caregivers (0.9%) participating on behalf of myeloma patients from 12 countries of treatment. Of the myeloma patients represented in the survey 33 (14%) were below 50 years, 59 (25.1%) were between 50 and 59 years, and 140 (49.6%) were 60 years and above. 3 patients (1.3%) did not indicate their age. More than half of the patients were male (128 or 54.5%) and 102 female (43.4%). 5 patients (2.1%) 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 144 participants (61.3%) were from the United Kingdom, 121 patients (51.5%) and 23 relatives and caregivers (9.8%). 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 the UK and those of other myeloma patients, patient relatives and caregivers.

**Sponsor:** This survey was made possible through an unrestricted grant from Celgene International.

## SUMMARY OF RESULTS

### Introductory remark

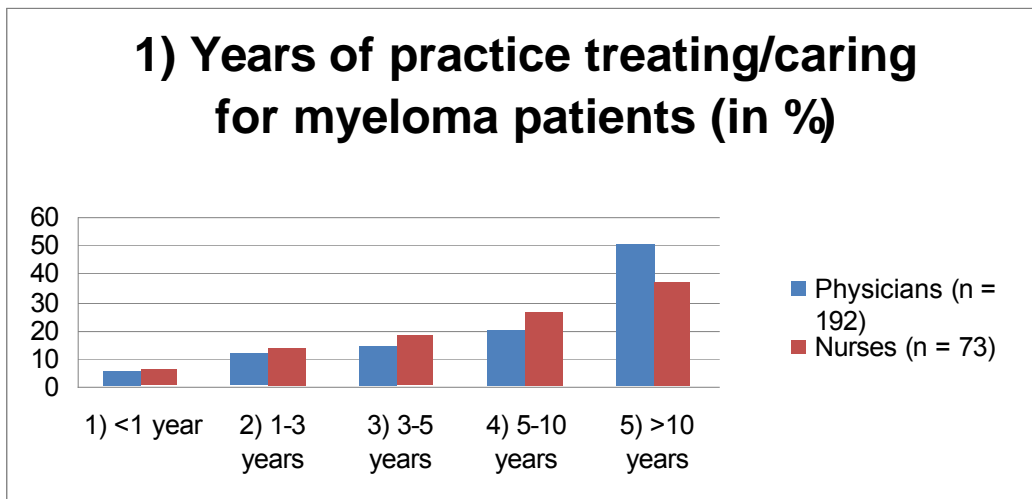
Because of the comparatively small number survey participants, this survey cannot be considered to be representative of the thoughts and opinions of all myeloma patients and healthcare professionals across Europe. The uneven distribution of participant groups across countries also does not allow comparing 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)

The majority of physicians (69.8%) and nurses (63%) who have responded to this question stated that they had been treating/caring for myeloma patients for more than 5 years.



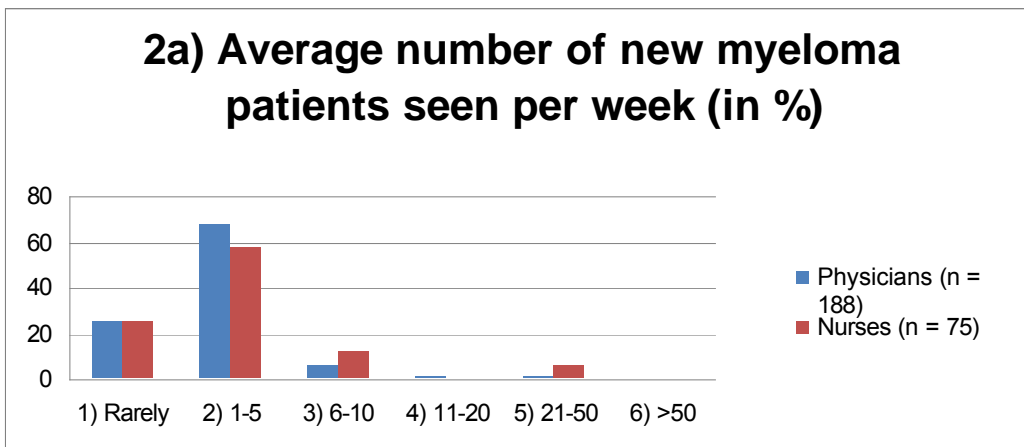
Graph 1) Years of practice treating/caring for myeloma patients (in %)

### Question 2a for physicians/nurses:

**“On average, how many new 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)

The majority of physicians (67.6%) and nurses (57%) who have answered this question stated that they see 1-5 new myeloma patients per week on average.

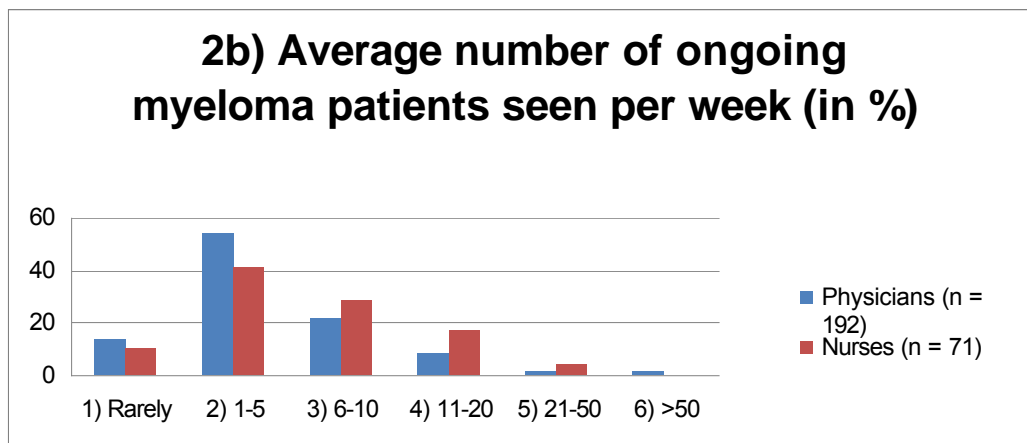


Graph 2) Average number of new myeloma patients seen per week (in %)

**Question 2b for physicians/nurses:**

“On average, how many ongoing 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)

The majority of physicians (53.7%) and 40.9% of the nurses who have answered this question stated that they see 1-5 ongoing myeloma patients per week on average.



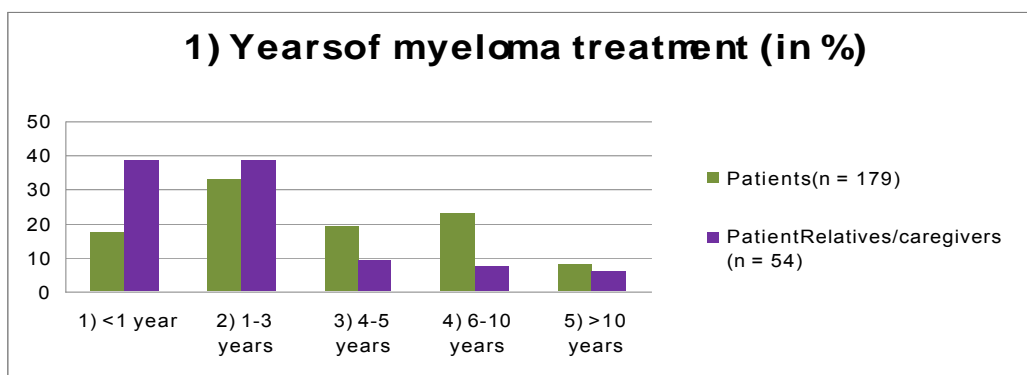
Graph 3) Average number of ongoing myeloma patients seen per week (in %)

**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 (50.3%) and more than three-quarters of the myeloma patients represented by their relatives or caregivers (78.8%) who responded to this question stated they had been receiving myeloma treatment for less than 1 year up to three years, and 49.7% of myeloma patients and 22.2% of myeloma patients represented by their relatives or caregivers stated they had been receiving myeloma treatment for more than 4 years.

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



Graph 4) Years of myeloma treatment (in %)

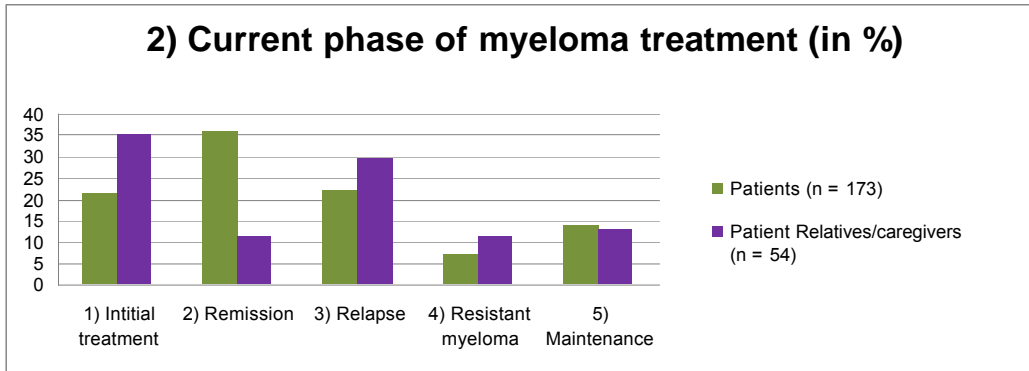
**Question 2 for patients/patient relatives/caregivers:**

“Which of the following best describes your (your family member’s) position with regard to your (your family member’s) myeloma?”  
(1) = Initial treatment; 2) = Remission; 3) = Relapse; 4) = Resistant myeloma; 5) = Maintenance

Almost half of the myeloma patients (49.7%) and almost one-quarter of the myeloma patients represented by their relatives or caregivers (24.1%) who responded to this question stated they were either in

remission or on maintenance treatment. About one-fifth of myeloma patients (21.4%) and one-third of the myeloma patients represented by their relatives or caregivers (35.2%) stated they were receiving initial treatment, and close to one-third of myeloma patients (28.9%) and 40.7% of the myeloma patients represented by their relatives or caregivers stated they had a relapse or resistant myeloma.

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



Graph 5) 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: “In the following overview, please tick those myeloma treatments that you are (your family member is) currently undergoing.

If you are (your family member is) not undergoing myeloma treatment at the moment, please underline the treatments that you have (your family member has) had in the past.”

- 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) = Orthopaedic interventions

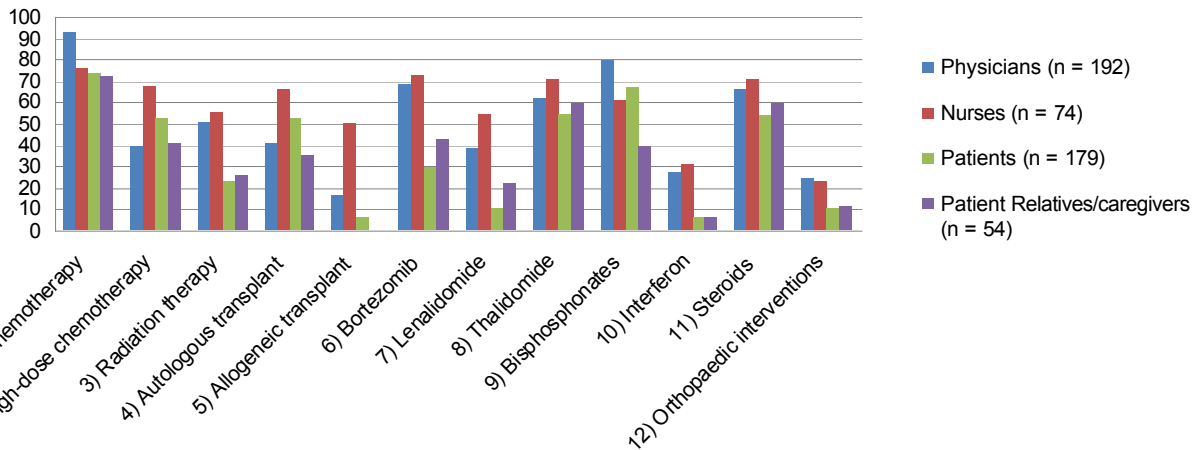
It was possible to tick more than one answer option.

According to the physicians who answered this question, the most frequent myeloma treatment option used is chemotherapy (92.8%), followed by bisphosphonates (79.2%), Bortezomib (68.2 %), steroids (66.2%), and Thalidomide (62%). According to nurses, the most frequent myeloma treatment option used is chemotherapy (75.7%), followed by Bortezomib (73%), Thalidomide and steroids (70.3% each), and high-dose chemotherapy (67.6%).

According to the myeloma patients who responded to this question, the most frequent myeloma treatment option received is chemotherapy (73.7%), followed by bisphosphonates (67%), steroids (53.6%), Thalidomide (54.2%), autologous transplant (52.5%) and high-dose chemotherapy (52%). 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 is chemotherapy (72.2%), followed by Thalidomide and steroids (59.3% each), Bortezomib (42.6%) and high-dose chemotherapy (40.7%).

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

### 3) Myeloma treatments used/received (in %)



Graph 6) Myeloma treatments used/received (in %)

#### Question 4:

– For healthcare professionals:

”How would you say myeloma treatment plans are usually determined in your institution?”

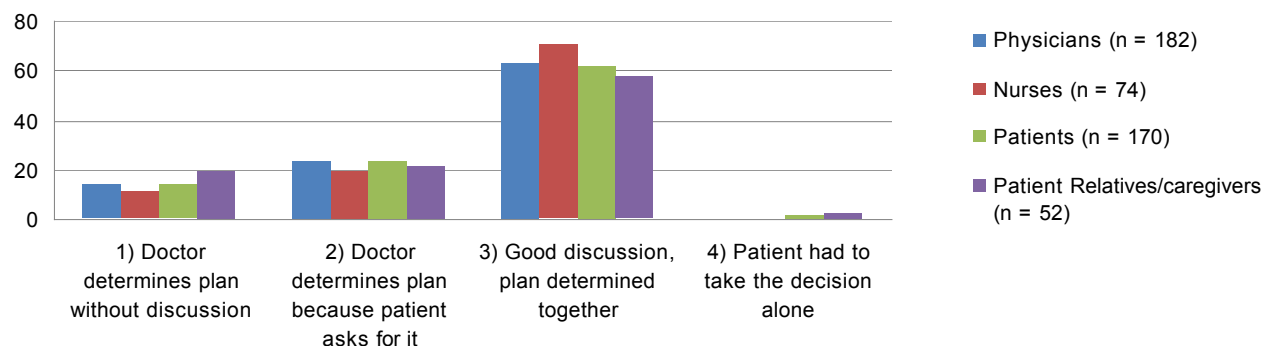
– For myeloma patients/relatives/caregivers:

”How would you say your (your family member’s) myeloma treatment plan was determined?”

1) = The doctor determines / determined the treatment plan and the patient has / I (my family member) had to accept it without discussion; 2) = The doctor determines / determined the treatment plan because the patient expects/asks / I (my family member) expected/asked her/him to do so; 3) = There is a good discussion between doctor and patient/ with the doctor and the treatment plan is / was determined together; 4) = The doctor doesn’t / didn’t want to take the relevant treatment decisions so the patient has / I (my family member) had to take them

The majority of physicians (63.2%), nurses (70.3%), myeloma patients (61.8%) and patient relatives and caregivers (57.7%) who have responded to this question stated that the myeloma treatment plan is usually determined together by the doctor and the patient, following a good discussion. However, about one-fifth of each group of participants stated that the doctor had to determine the treatment plan because the patient expected or asked her/him to do so, and more than one in ten physicians (13.7%), nurses (10.8%), myeloma patients (13.5%) and close to one in five patient relatives and caregivers (19.2%) stated that the doctor determined the treatment plan and the patients had to accept it without discussion.

### 4) Determination of treatment plan (in %)



Graph 7) Determination of myeloma treatment plan (in %)

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

**Question 5:**

– For healthcare professionals:

“How familiar are the myeloma patients you see with their respective treatment plan?”

– For myeloma patients/relatives/caregivers:

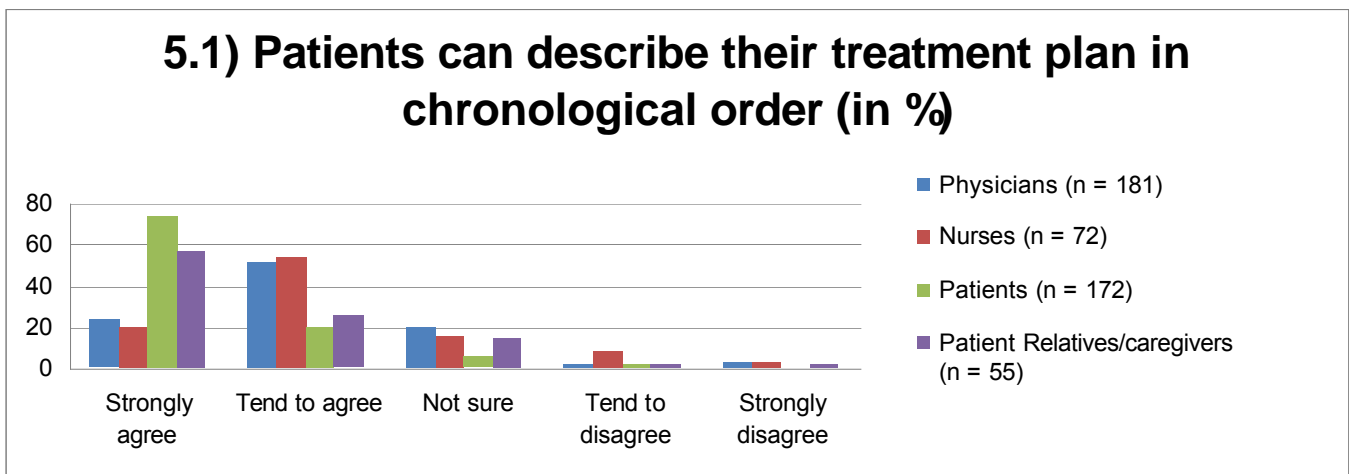
“How familiar are you (is your family member) with your (her/his) myeloma treatment plan?”

1) = [Myeloma patients] could describe their respective treatment plan in chronological order; 2) = [Myeloma patients] could list all medications currently used to treat their myeloma; 3) = [Myeloma patients] know the purpose of each medication currently used to treat their myeloma; 4) = [Myeloma patients] know how and when to take/administer each of these medications; 5) = [Myeloma patients] know about the potential side effects of each of these medications

1) = Strongly agree; 2 = Tend to agree; 3 = Not sure; 4 = Tend to disagree; 5 = Strongly disagree

**5.1) Ability to describe treatment plan in chronological order**

Almost three-quarters of myeloma patients (73.3%) and more than half of the patient relatives and caregivers (56.4%) who answered this question “strongly agreed” that myeloma patients can describe their respective treatment plan in chronological order. However, only about one in four physicians (23.8%) and one in five nurses (19.4%) shared this opinion. More than half of the physicians (51.4%) and nurses (54.2%) only “tend to agree” that their myeloma patients can chronologically describe their treatment plan – an opinion shared by about one in five patients (19.8%) and one in four patient relatives and caregivers (25.5%). One in five physicians (19.9%), about one in six nurses (15.3%) and one in seven patient relatives and caregivers (14.6%) stated that they were “not sure” if myeloma patients can describe their respective treatment plan in chronological order.



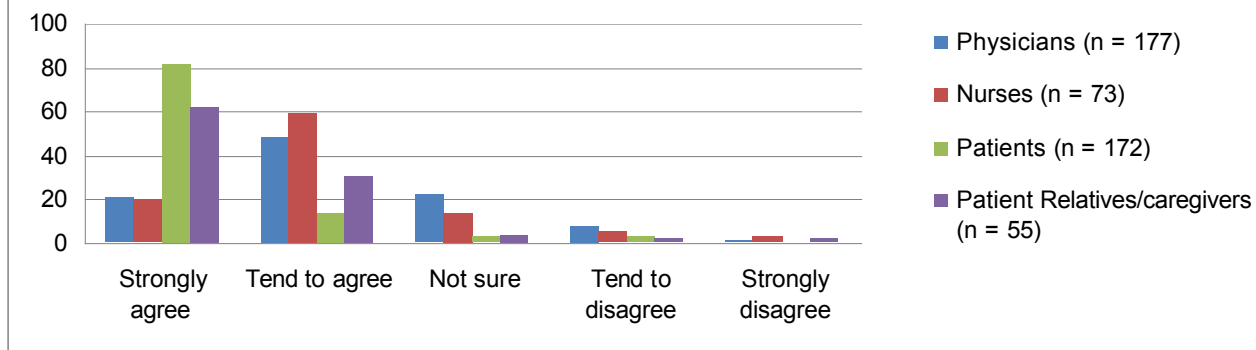
Graph 8) Myeloma patient ability to describe treatment plan in chronological order (in %)

There were no significant differences observed between the opinions expressed by myeloma patients, patient relatives and caregivers from the UK and those stated by other myeloma patients, patient relatives and caregivers.

**5.2) Ability to list medications**

More than 80% of myeloma patients (81.4%) and about two-thirds of the patient relatives and caregivers (61.9%) who responded to this question “strongly agreed” that myeloma patients can list their medications, whereas only one in five physicians (20.3%) and nurses (19.2%) shared this point of view. Almost half of the physicians (48.6%) and more than half of the nurses (58.9%) – and almost one-third of patient relatives and caregivers (30.9%) – responded to this question saying that they only “tend to agree,” and almost one-quarter of the physicians responding to this question (22%) said they were “not sure” if their myeloma patients can list their medications.

## 5.2) Patients can list their medications (in %)



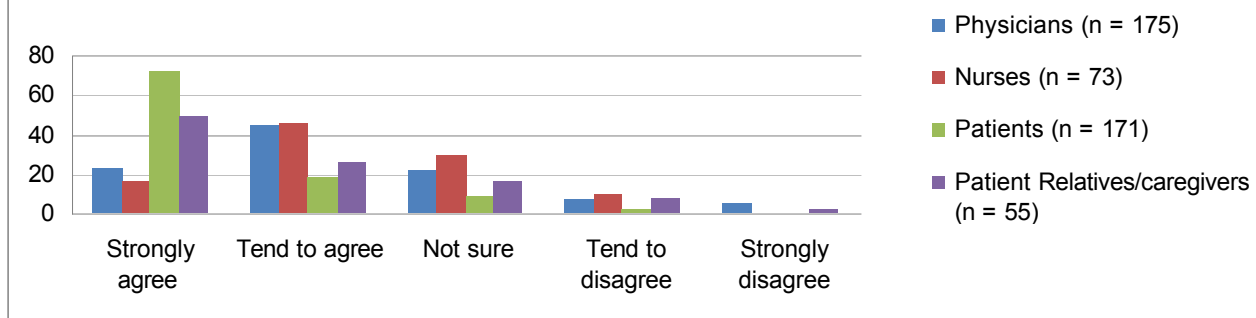
Graph 9) Myeloma patient ability to list their medications (in %)

There were no significant differences observed between the opinions expressed by myeloma patients, patient relatives and caregivers from the UK and those stated by other myeloma patients, patient relatives and caregivers.

## 5.3) Knowledge of purpose of each medication

Asked whether they feel that myeloma patients know the purpose of each of their medications, the majority of physicians (44.6%) and nurses (45.2%) responding to this question said that they “tend to agree”, about one-fifth of physicians (22.3%) and one-sixth of nurses (16.4%) stated that they “strongly agree” and about another one-fifth of physicians (21.7%) and almost one-third (28.8%) of nurses responded that they were “not sure.” Almost three-quarters of patients (71.4%) and about half of the patient relatives and caregivers (49.1%) who responded to this question “strongly agreed” that myeloma patients know the purpose of each of their medications, and about one in five patients (18.1%) and one in four patient relatives and caregivers (25.5%) said that they “tend to agree.”

## 5.3) Patients know the purpose of each medication (in %)



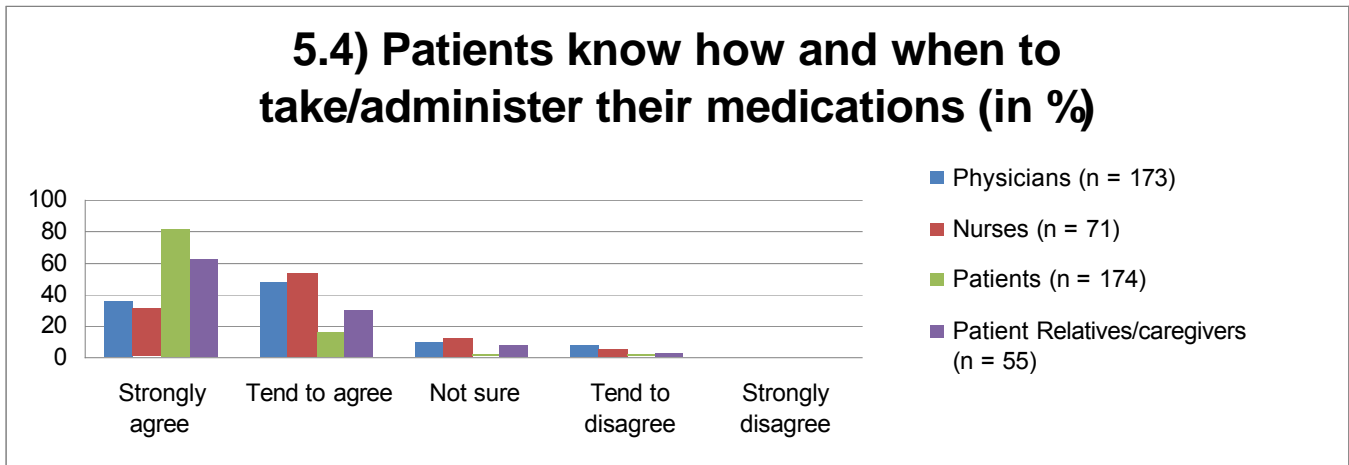
Graph 10) Myeloma patient knowledge of purpose of each medication (in %)

There were no significant differences observed between the opinions expressed by myeloma patients, patient relatives and caregivers from the UK and those stated by other myeloma patients, patient relatives and caregivers.

## 5.4) Knowledge about how and when to take/administer medications

More than three-quarters of myeloma patients (81.6%) and almost two-thirds of patient relatives and caregivers (61.8%) who answered this question “strongly agreed” that myeloma patients know how and when to take/administer their medications, an opinion shared by about one-third of physicians (35.8%)

and nurses (31%). About half of the physicians (46.7%) and nurses (53.5%) and about one-third of patient relatives and caregivers (29.1%) answered that they “tend to agree” with this point of view.

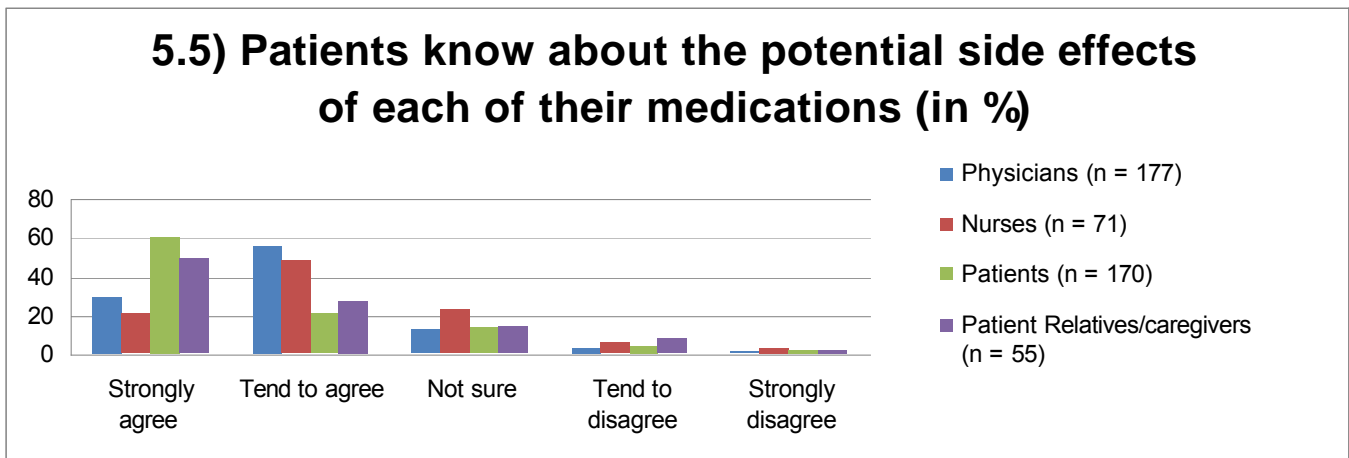


Graph 11) Myeloma patient knowledge about how and when to take/administer their medications (in %)

There were no significant differences observed between the opinions expressed by myeloma patients, patient relatives and caregivers from the UK and those stated by other myeloma patients, patient relatives and caregivers.

### 5.5) Knowledge about the potential side effects of medications

The lowest values of reported patient familiarity with myeloma treatment plans were seen in response to the question about the knowledge of myeloma patients about the potential side effects of each of their medications. About one on five myeloma patients (18.8%) and close to one-quarter of patient relatives and caregivers (23.6%) who have responded to this question said that they are either “not sure” if, or “tend to disagree” or “strongly disagree” that myeloma patients know about the potential side effects of each of their medications, a point of view that is shared by about one in six physicians (15.8%) and almost one-third of the nurses (31%) who have answered this question. Close to two-thirds of myeloma patients (60.6%), almost half of patient relatives and caregivers (49.1%), about one-quarter of physicians (28.8%) and about one-fifth of nurses (21.1%) “strongly agreed” that myeloma patients know about the potential side effects of each of their medications, and about half of the physicians (55.4%) and nurses (47.9%) but only about one-fifth of myeloma patients (20.6%) and about one-quarter of patient relatives and caregivers (27.3%) said that they “tend to agree” with this opinion.



Graph 12) Myeloma patient knowledge about the potential side effects of each of their medications (in %)

There were no significant differences observed between the opinions expressed by myeloma patients, patient relatives and caregivers from the UK and those stated by other myeloma patients, patient relatives and caregivers.

### Question 6:

– For healthcare professionals:

“Are you satisfied with the level of information given to myeloma patients regarding the importance of correctly following their respective treatment plan?”

– For myeloma patients/relatives/caregivers:

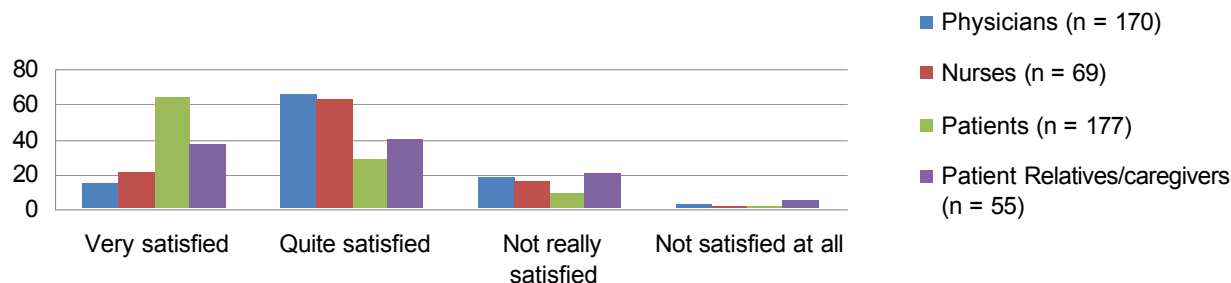
“Are you satisfied with how the doctor and/or the nurse has informed you (your family member) about the importance of correctly following your (your family member’s) myeloma treatment plan?”

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

About one in five physicians (19.4%), about one in six nurses (17.4%) and almost one in four patient relatives and caregivers (23.6%) who responded to this question were “not really satisfied” or “not satisfied at all” with the level of information given to myeloma patients regarding the importance of correctly following their respective treatment plan. Interestingly, the level of dissatisfaction was the lowest among myeloma patients themselves where only about one in twelve (8.5%) complained about this issue. More than nine in ten myeloma patients (91.5%) who answered this question reported that they were either “very satisfied” (63.4%) or “quite satisfied” (27.7%) with how the doctor and/or the nurse had informed them about the importance of correctly following their respective treatment plan, and about three-quarters of patient relatives and caregivers (76.4%) had the same opinion. While about two-thirds of physicians (65.9%) and nurses (62.3%) stated that they were “quite satisfied”, only about one in seven physicians (14.7%) and one in five nurses (20.3%) who responded to this question were “very satisfied” with the level of information given to myeloma patients concerning following their treatment plan.

Of those survey participants who stated they were “not really satisfied” or “not satisfied at all,” 9 physicians (27.3%), 4 nurses (33.3%), 13 myeloma patients (86.7%) and 13 patient relatives/caregivers (100%) also provided reasons for not being satisfied with the level of information given to myeloma patients regarding the importance of correctly following their respective treatment plan. The reasons given by physicians included lack of time, lack of information and education (of both physicians and patients), lack of “special specialists (explainers, psychologists),” difficulties in explaining for physicians and lack of understanding from older patients, cultural issues/differences, and language issues. Nurses mainly stressed the complexity of treatment and related information and the need for written instructions. Myeloma patients repeatedly complained about the lack of time of the doctor, frequent changes of doctors, the lack of knowledge/competence of the doctor, lack of information, difficulties understanding instructions, and the need for verbal or written guidance. Patient relatives and caregivers repeatedly stressed the lack of interest, responsiveness, clarity and empathy on the side of the doctor as well as cultural issues, and, again the lack of information. A corresponding quote: “On discharge from hospital, a large bag of drugs was handed over without explanation. Since then and after a phone call to the hospital, we have followed the plan to the letter.”

## 6) Satisfaction concerning the level of information given to patients regarding importance of correctly following treatment plan (in %)



Graph 13) Satisfaction concerning the level of information given to patients regarding the importance of correctly following their treatment plan (in %)

There were no significant differences observed between the opinions expressed by myeloma patients, patient relatives and caregivers from the UK and those stated by other myeloma patients, patient relatives and caregivers.

### **Question 7:**

“From your experience, to what extent would you say the following factors have a negative effect on whether a myeloma patient correctly follows her/his treatment plan?”

- 1) = Lack of instructions from doctor/nurse; 2) = Poor rapport with doctor/nurse; 3) = Lack of monitoring from doctor/nurse; 4) = Unclear treatment purpose; 5) = Complicated treatment plan; 6) = Lack of symptoms; 7) = Failure of treatment to show effect; 8) = Treatment side effects; 9) = Frequent changes of treatment plan; 10) = Frequent changes of medical professionals; 11) = Physical difficulties (e.g., difficulties to swallow; travel to place of treatment; etc.); 12) = Forgetfulness; 13) = Cost of drugs; 14) = Lack of psycho-social/emotional support
- 1) = Very much; 2) = Quite a bit; 3) = Neutral; 4) = Not very much; 5) = Not at all

The survey question about factors having a negative effect on whether a myeloma patient correctly follows her/his treatment plan was divided into 14 sub questions and each of them could be answered by indicating the extent to which the respondents felt the particular factor had an impact on treatment compliance.

Detailed graphs illustrating the opinions expressed in response to each individual sub question are shown in the “Additional Graphs” section at the end of this report.

All groups participating in this survey agreed that lack of instructions from the doctor or nurse is the factor having the most negative effect on myeloma treatment compliance (32.2% of physicians who responded to this particular sub question, 43.5% of nurses, 33.9% of myeloma patients, 43.6% of patient relatives and caregivers).

The second-most negative factor regarding treatment compliance according to physicians is the cost of drugs (32%), followed by unclear treatment purpose (29.4%), poor rapport with the doctor or nurse (29.3%), the complicated treatment plan (26.5%), lack of psycho-social/emotional support (24.1%), and frequent changes of medical professionals (23.9%).

According to the nurses who responded to this question, the factor that has the second-most negative effect on a myeloma patient's correctly following of the treatment plan is a poor rapport with the doctor or nurse (27.1%), followed by failure of the treatment to show effect (24.6%), lack of monitoring from the doctor or nurse, treatment side effects and physical difficulties (all 22.9%), and unclear treatment purpose and forgetfulness (19.1% each).

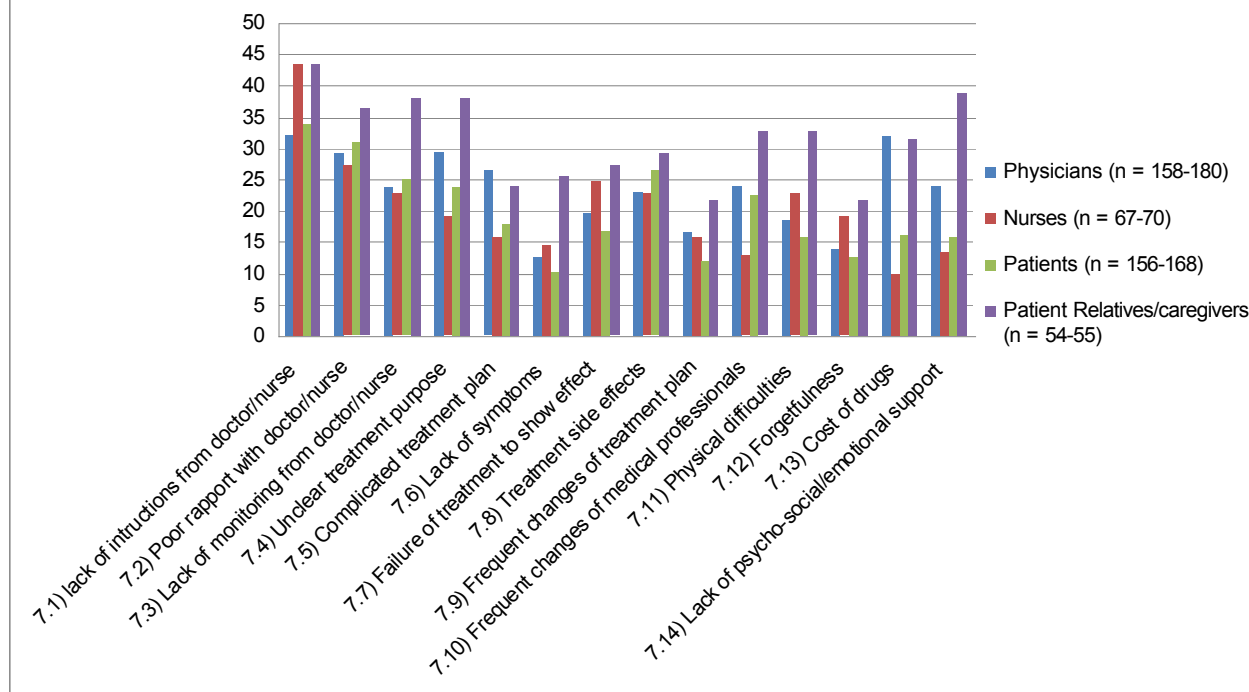
Similar to the nurses, the myeloma patients who answered this question stated that a poor rapport with the doctor or nurse is the factor having the second-most negative effect on myeloma treatment compliance (30.9%), followed by treatment side effects (26.4%), lack of monitoring from the doctor or nurse (25%), unclear treatment purpose (23.8%), frequent changes of medical professionals (22.6%) and the complicated treatment plan (17.8%).

For the patient relatives and caregivers who answered this question, the lack of psycho-social/emotional support was the second-most negative factor regarding myeloma treatment compliance (38.9%), followed by lack of monitoring from the doctor or nurse and unclear treatment purpose (all 38.1%), poor rapport with the doctor or nurse (36.4%), frequent changes of medical professionals and physical difficulties (32.7% each).

There were no significant differences observed between the opinions expressed by myeloma patients, patient relatives and caregivers from the UK and those stated by other myeloma patients, patient relatives and caregivers.

The following graph illustrates only those factors that were perceived to have a very negative effect on the correct following of the myeloma treatment plan.

## 7) Factors having a very negative effect on the correct following of the treatment plan (in %)



Graph 14) Factors having a very negative effect on the correct following of the treatment plan (in %)

### Question 8:

“Myeloma treatment can have many side effects. Taking nerve disorders as an example, would you say that Peripheral Neuropathy makes it difficult for a myeloma patient ...:”

- 1) = to cope with myeloma? 2) = to correctly follow her/his treatment plan?  
 3) = to stay on myeloma treatment? 4) = to carry on with her/his daily activities?  
 1) = Very much; 2) = Quite a bit; 3) = Neutral; 4) = Not very much; 5) = Not at all

This survey question was again divided into 4 sub questions, each of which could be answered by indicating the extent to which the respondents felt the particular area was affected by Peripheral Neuropathy (a nerve disorder affecting hands and feet that can result in abnormal or decreased sensation or burning/tingling). Detailed graphs for each individual sub question are shown in the “Additional Graphs” section at the end of this report.

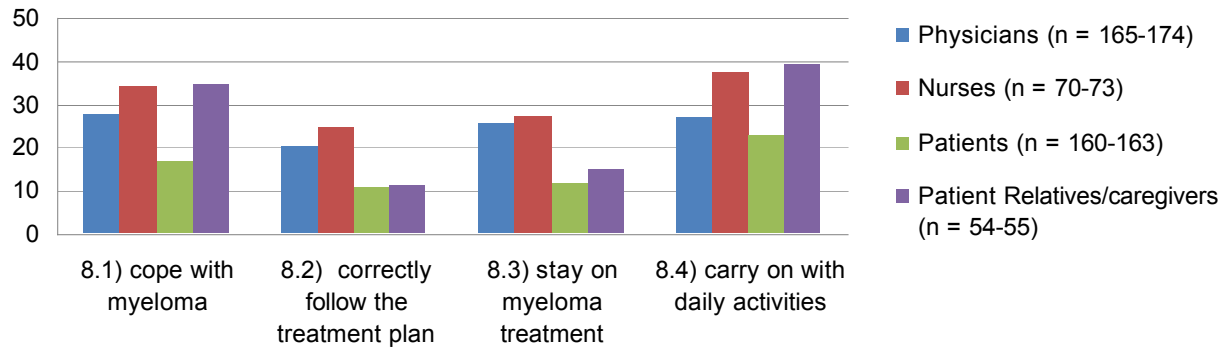
According to the physicians who responded to this question, coping with myeloma is the area that is most affected by Peripheral Neuropathy (27.6% of physicians who responded to this particular sub question), followed by carrying on with daily activities (26.7%), staying on myeloma treatment (25.4%) and correctly following the treatment plan (20.1%).

Nurses, patients and patient relatives and caregivers who answered this question agreed that carrying on with daily activities is the area most affected by Peripheral Neuropathy (37.5%, 22.7% and 38.9% respectively), followed by coping with myeloma (34.3%, 16.67%, 34.6%), staying on myeloma treatment (27.1%, 11.25%, 14.81%) and correctly following the treatment plan (24.7%, 10.6%, 10.9%).

There were no significant differences observed between the opinions expressed by myeloma patients, patient relatives and caregivers from the UK and those stated by other myeloma patients, patient relatives and caregivers.

The following graph illustrates only the areas in which Peripheral Neuropathy was perceived to have a very negative impact.

## 8) Peripheral Neuropathy makes it very difficult to ... (in %)



Graph 15) Peripheral Neuropathy makes it very difficult to ... (in %)

### Question 9:

– For healthcare professionals:

“On the following scale, please mark with an X how you would rate the overall treatment compliance of myeloma patients treated in your institution (0% = no compliance; 100% = full compliance):”

“If the overall patient compliance is below 100%, please give one or two examples for non-compliance:”

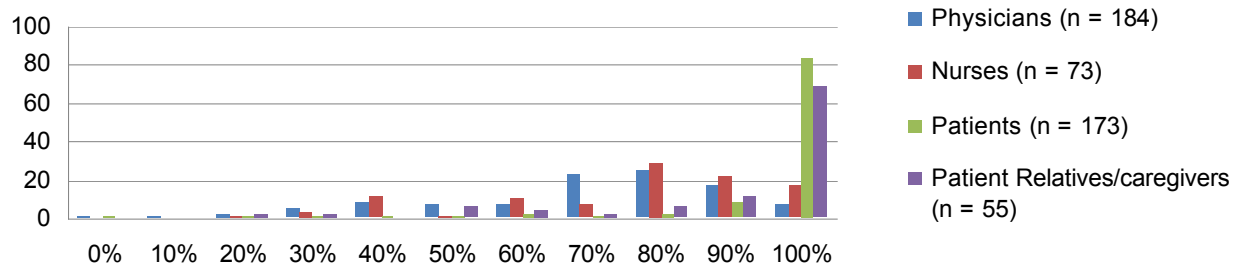
– For myeloma patients/relatives/caregivers:

“On the following scale, please mark with an X how you would rate your own (your family member’s) overall compliance in the course of myeloma treatment (0% = no compliance; 100% = full compliance):”

“If your (your family member’s) compliance is below 100%, please give one or two examples for non-compliance:”

Of the myeloma patients, patient relatives and caregivers who answered this question, a large majority (91.9% and 80% respectively) said that overall myeloma patient treatment compliance was either 90% or 100%. The majority of the nurses who responded to this question stated that the overall treatment compliance was mainly between 80% and 100% (67.1%), whereas the majority of physicians who expressed their opinion in response to this question saw the overall myeloma treatment compliance somewhere between 70% and 90% (64.1%).

## 9) Overall treatment compliance of myeloma patients (in %)



Graph 16) Overall treatment compliance of myeloma patients (in %)

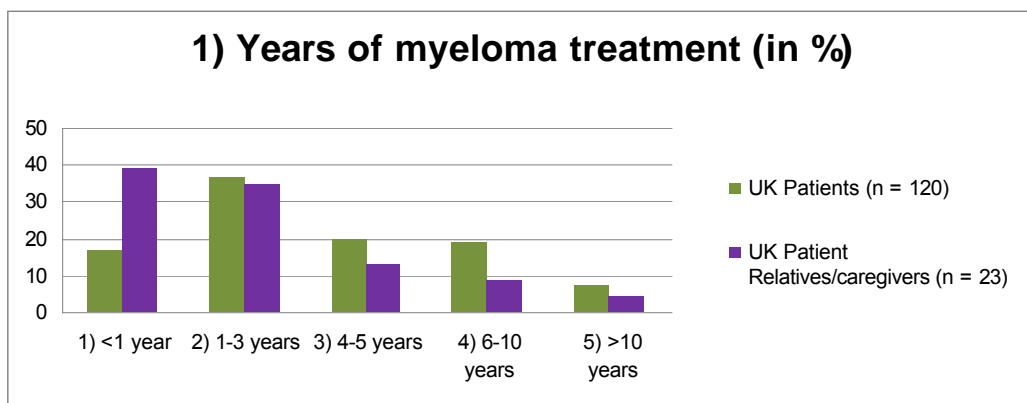
Graphs illustrating the differences between myeloma patients, patient relatives and caregivers from the UK and the other myeloma patients, patient relatives and caregivers are shown in the “Additional Graphs” section at the end of this report.

When asked in the second part of the question to give one or two examples for non-compliance, 55 physicians, 13 nurses, 29 myeloma patients and 18 patient relatives and caregivers replied. The following were the most frequently stated examples:

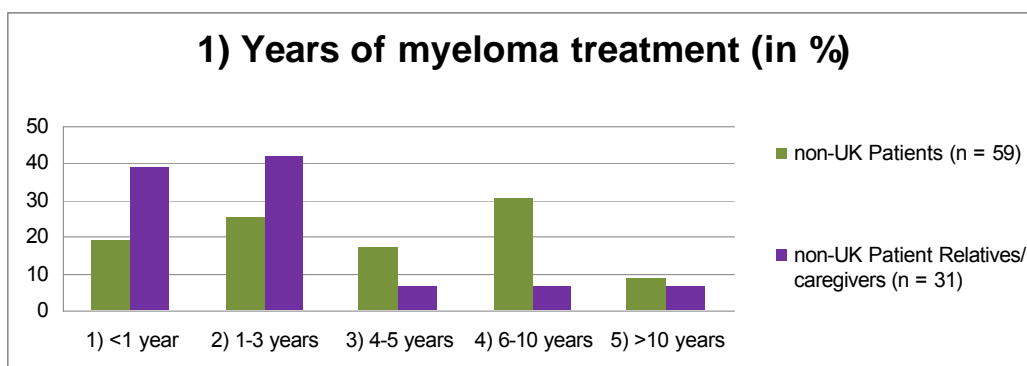
- Side effect-related issues (mentioned by 21 physicians (38.2% of those who stated examples), 1 nurse (7.7%), 10 patients (35.7%) and 4 patient relatives and caregivers (22.2%))
- Cost/insurance-related issues (mentioned by 12 physicians (21.8%))
- Patient age-related issues (mentioned by 4 physicians (7.3%) and 1 nurse (7.7%))
- Patient forgetfulness-related issues (mentioned by 3 physicians (5.5%), 1 nurse (7.7%) and 3 patients (10.3%))
- Issues related to lack of psycho-social support (mentioned by 3 physicians (5.5%), 1 nurse (7.7%), 2 patients (6.9%) and 3 patient relatives and caregivers (16.7%))
- Issues related to (frequent) changes of the treatment plan (mentioned by 2 physicians (3.6%) and 1 patient relative/caregiver (5.6%))
- Issues related to lack of information (mentioned by 1 nurse (7.7%) and 3 patients (10.3%))

## Additional Graphs

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

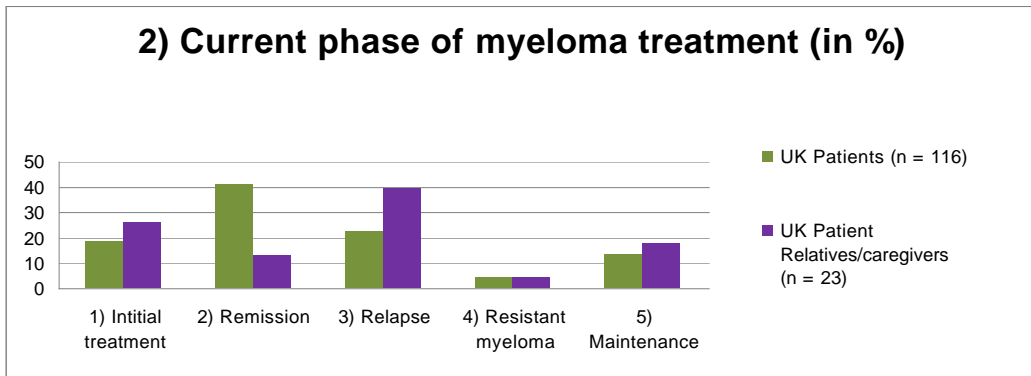


Graph 4a) Years of myeloma treatment as indicated by UK patients, patient relatives and caregivers (in %)

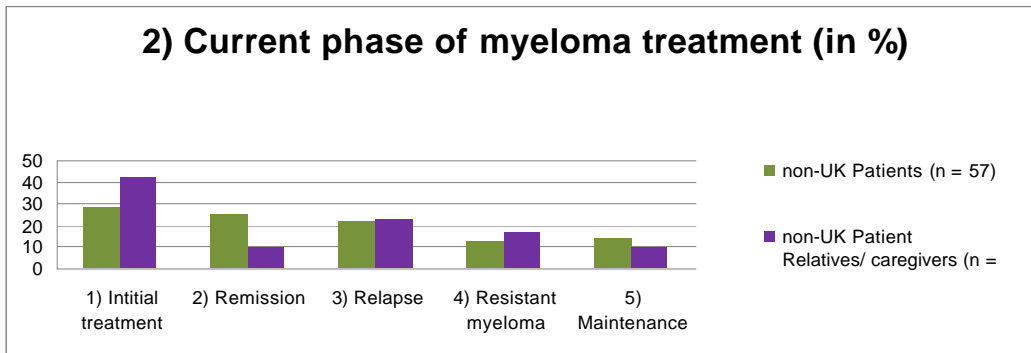


Graph 4b) Years of myeloma treatment as indicated by non-UK patients, patient relatives and caregivers (in %)

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

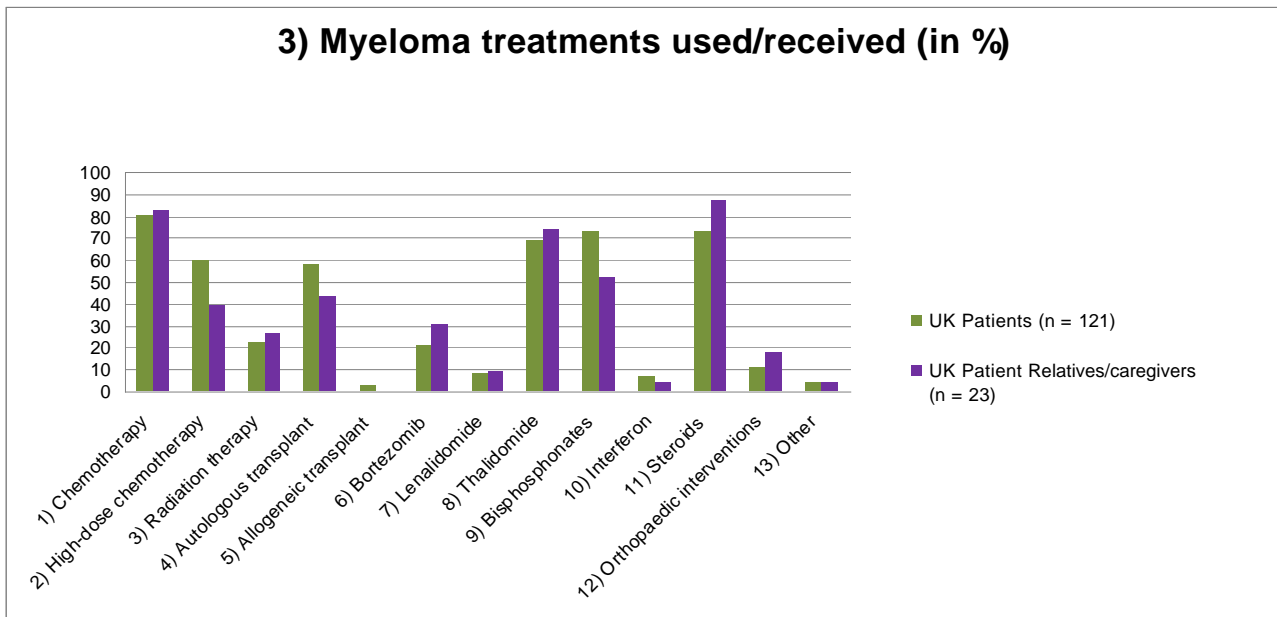


Graph 5a) Current phase of myeloma treatment as indicated by UK patients, patient relatives and caregivers (in %)



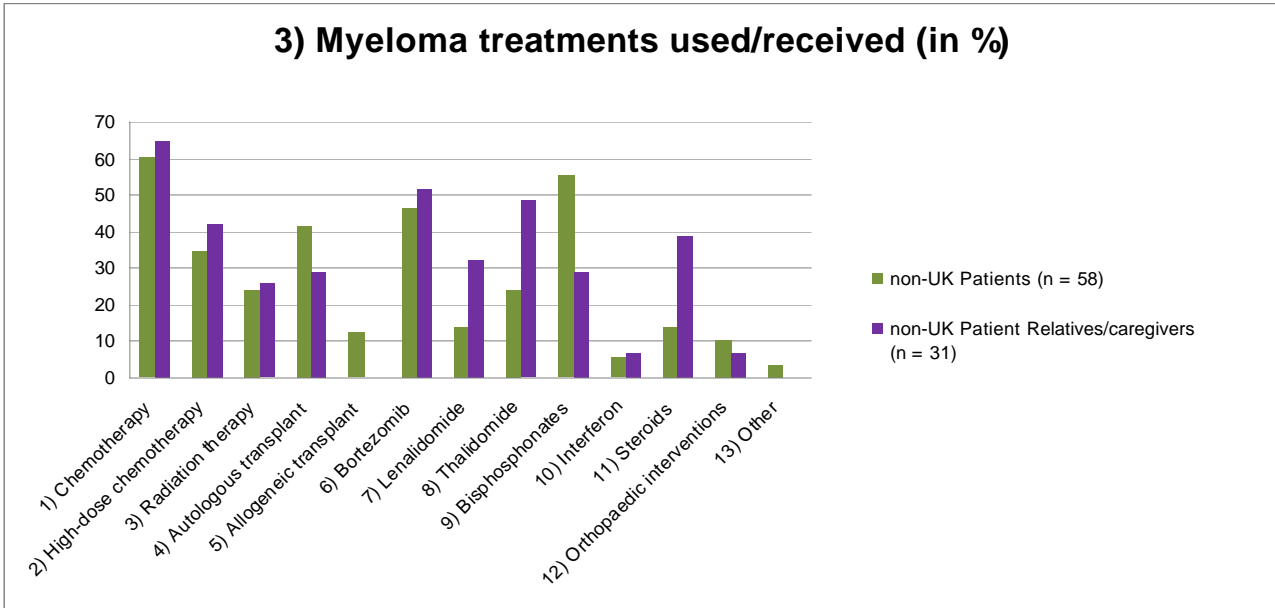
Graph 5b) Current phase of myeloma treatment as indicated by non-UK patients, patient relatives and caregivers (in %)

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



Graph 6a) Myeloma treatments received as indicated by UK patients, patient relatives and caregivers (in %)

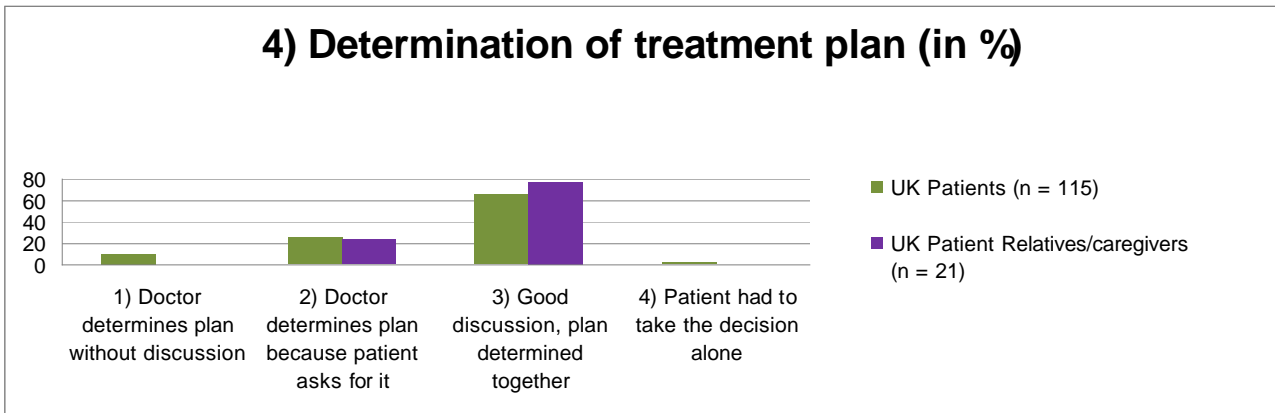
### 3) Myeloma treatments used/received (in %)



Graph 6b) Myeloma treatments received as indicated by non-UK patients, patient relatives and caregivers (in %)

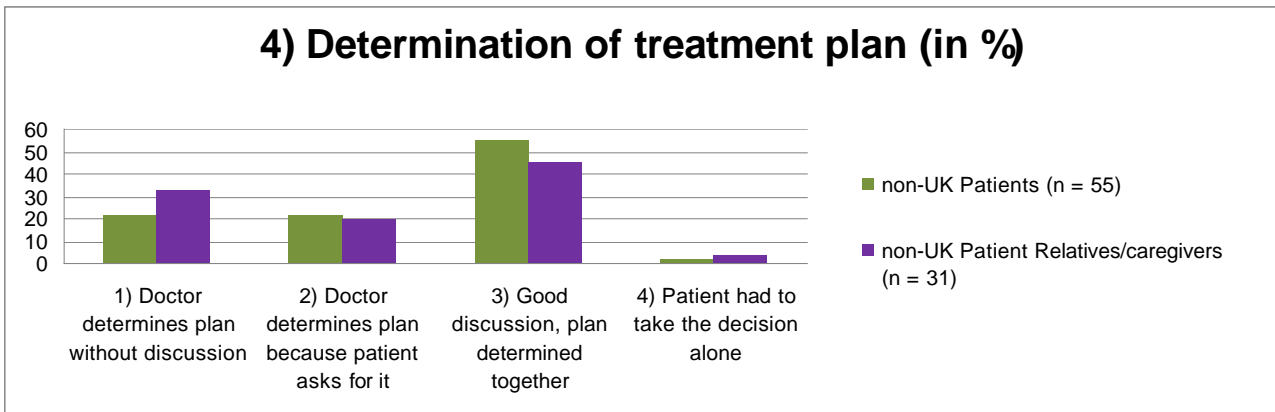
### Question 4 for patients/patient relatives/caregivers

#### 4) Determination of treatment plan (in %)



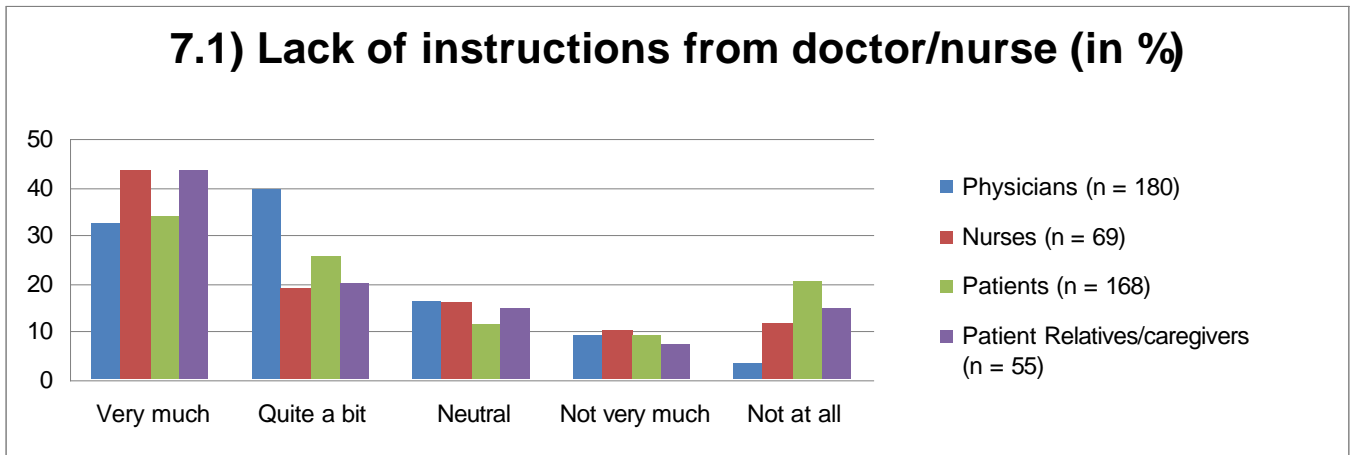
Graph 7a) Determination of treatment plan as indicated by UK patients, patient relatives and caregivers (in %)

#### 4) Determination of treatment plan (in %)

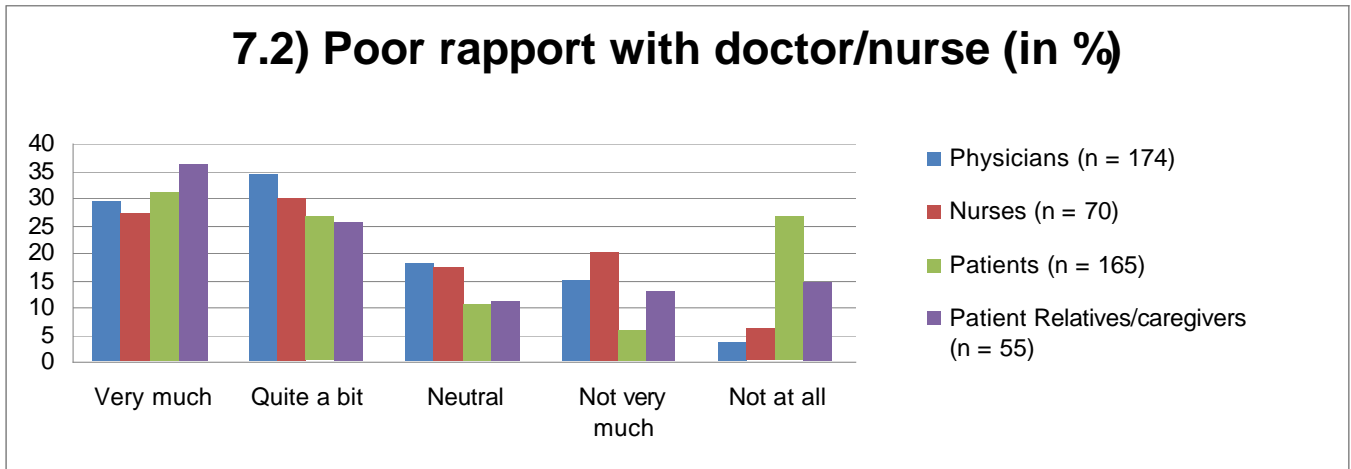


Graph 7b) Determination of treatment plan as indicated by non-UK patients, patient relatives and caregivers (in %)

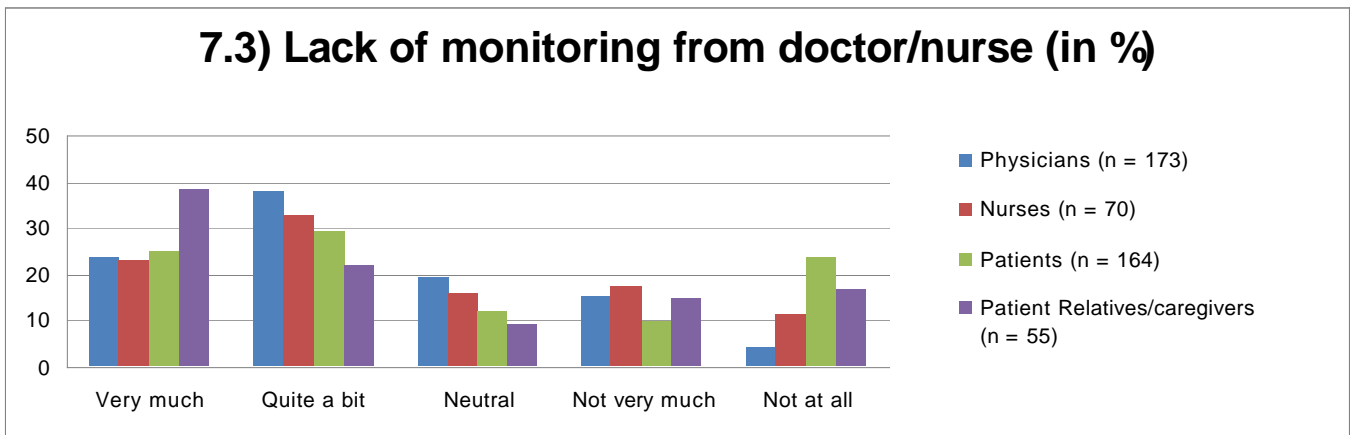
**Question 7**



Graph 14a) Lack of instructions from doctor/nurse (in %)

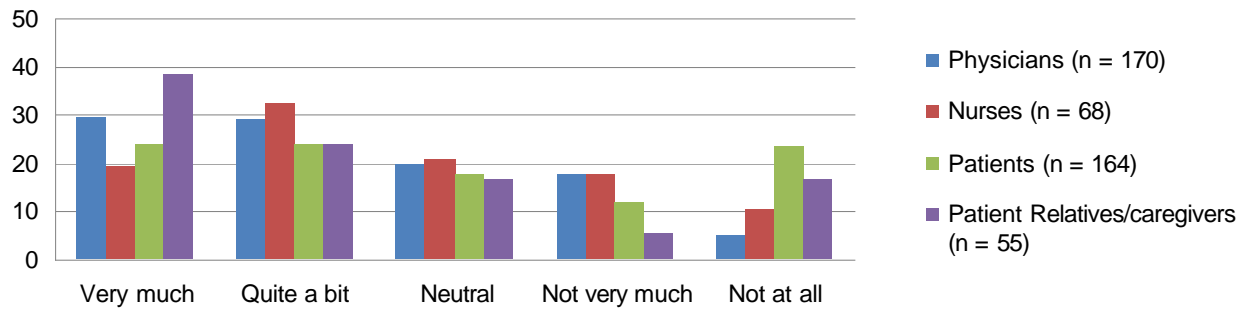


Graph 14b) Poor rapport with doctor/nurse (in %)



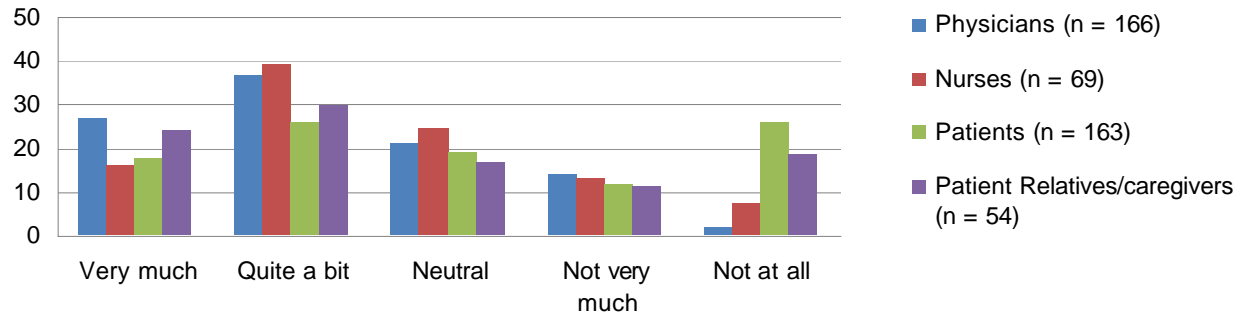
Graph 14c) Lack of monitoring from doctor/nurse (in %)

## 7.4) Unclear treatment purpose (in %)



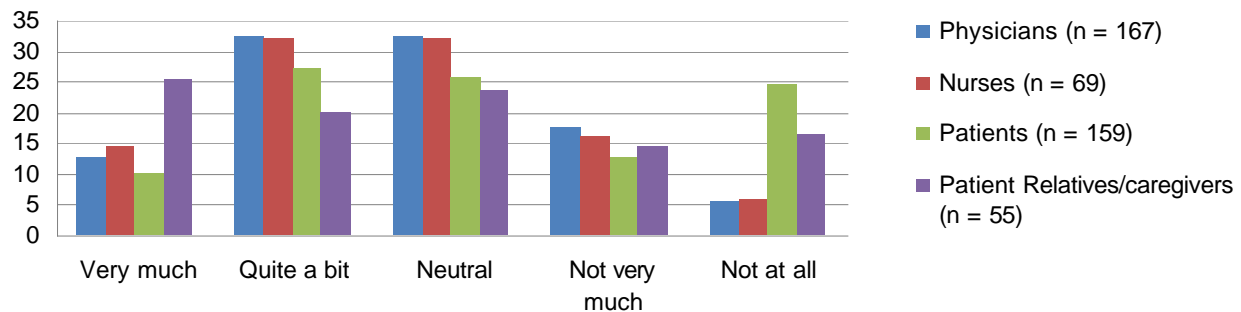
Graph 14d) Unclear treatment purpose (in %)

## 7.5) Complicated treatment plan (in %)



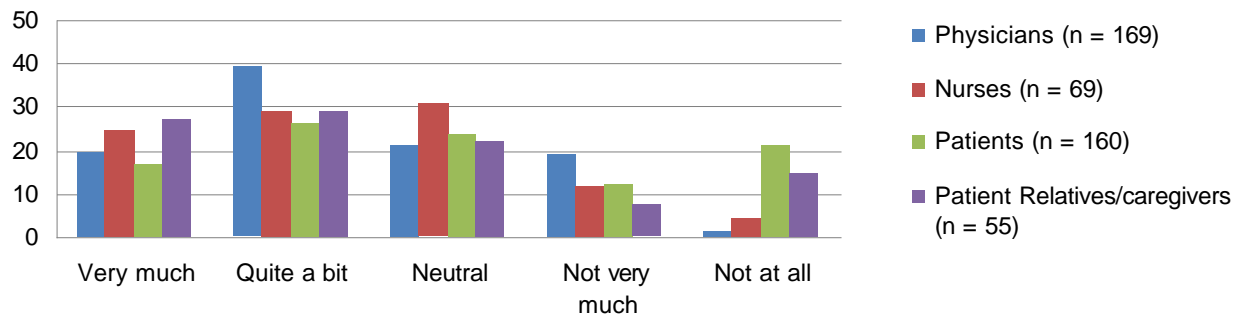
Graph 14e) Complicated treatment plan (in %)

## 7.6) Lack of symptoms (in %)



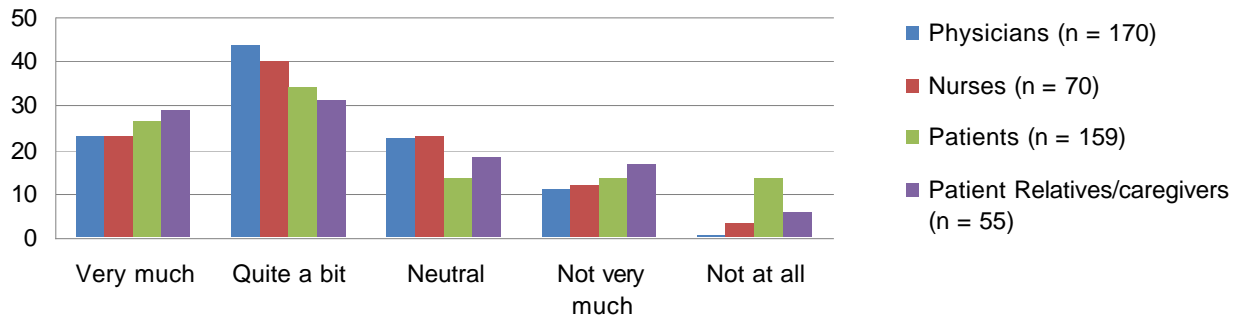
Graph 14f) Lack of symptoms (in %)

## 7.7) Failure of treatment to show effect (in %)



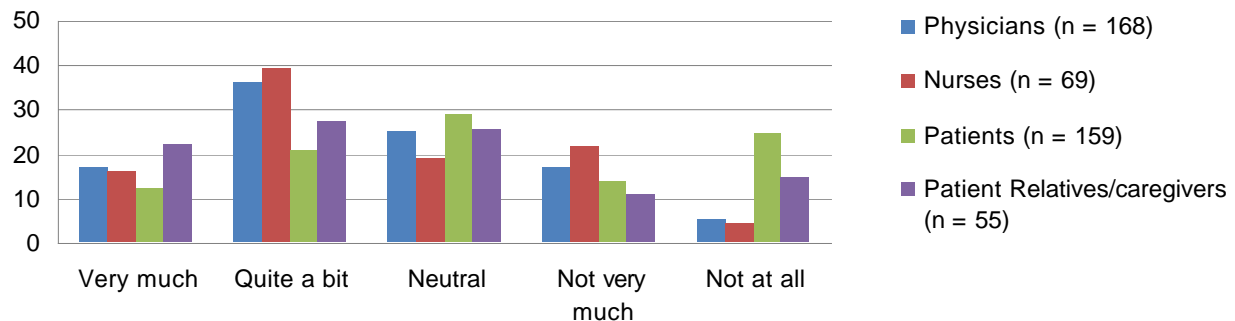
Graph 14g) Failure of treatment to show effect (in %)

## 7.8) Treatment side effects (in %)



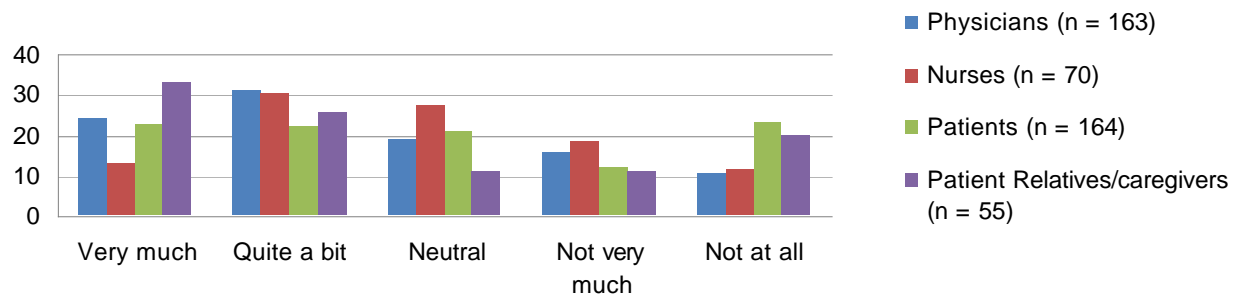
Graph 14h) Treatment side effects (in %)

## 7.9) Frequent changes of treatment plan (in %)



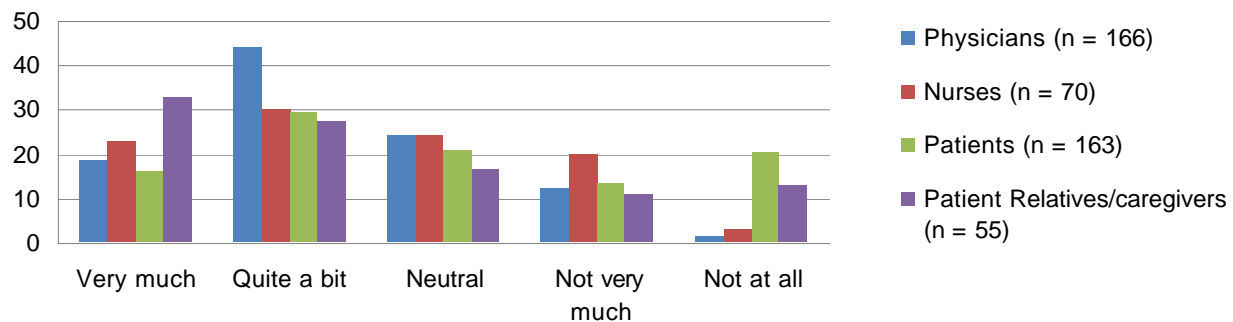
Graph 14i) Frequent changes of treatment plan (in %)

## 7.10) Frequent changes of medical professionals (in %)



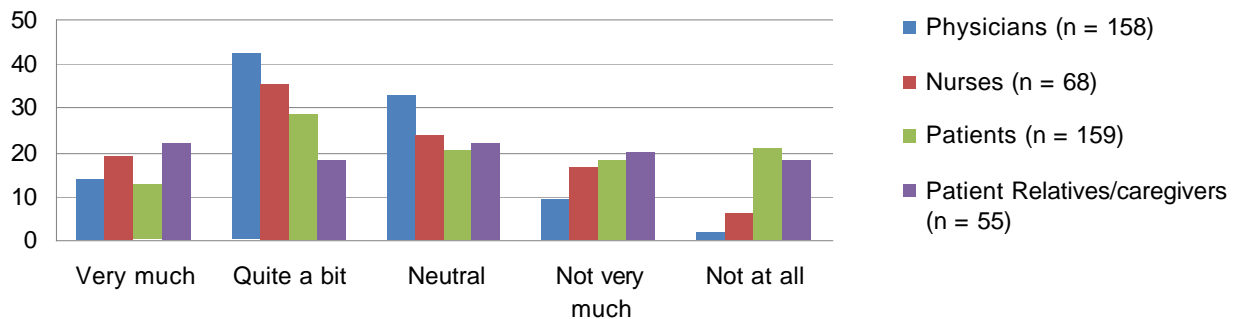
Graph 14j) Frequent changes of medical professionals (in %)

## 7.11) Physical difficulties (in %)



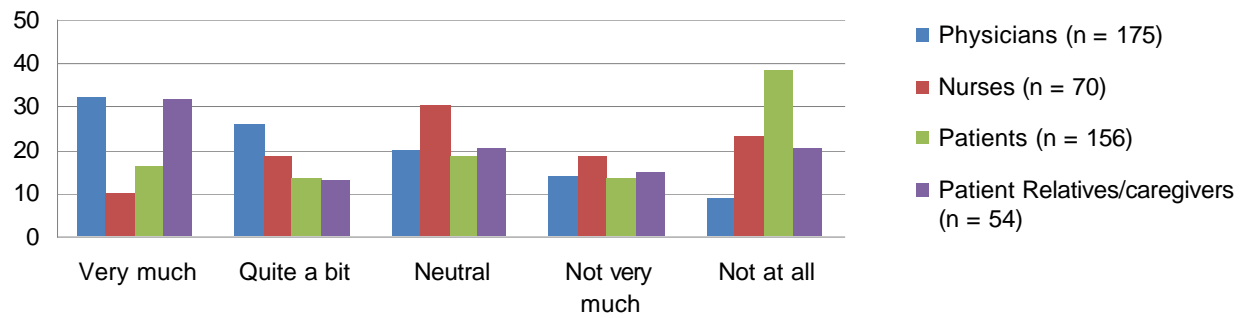
Graph 14k) Physical difficulties (in %)

## 7.12) Forgetfulness (in %)



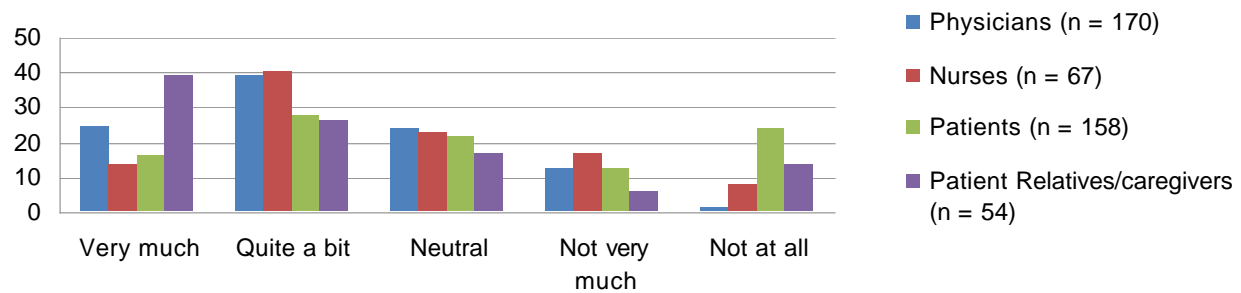
Graph 14l) Forgetfulness (in %)

### 7.13) Cost of drugs (in %)



Graph 14m) Cost of drugs (in %)

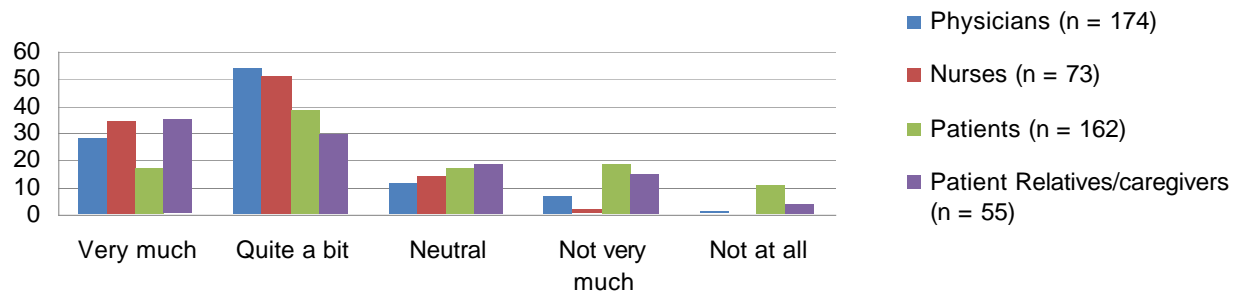
### 7.14) Lack of psycho-social/emotional support (in %)



Graph 14n) Lack of psycho-social/emotional support (in %)

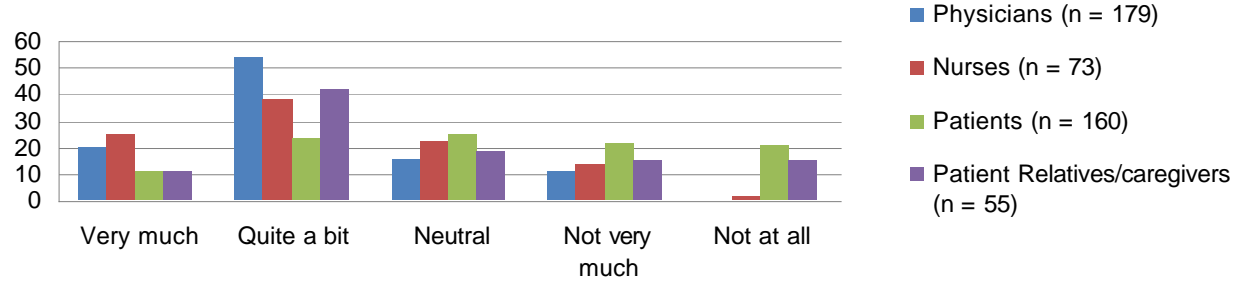
## Question 8

### 8.1) Peripheral Neuropathy makes it difficult to cope with myeloma (in %)



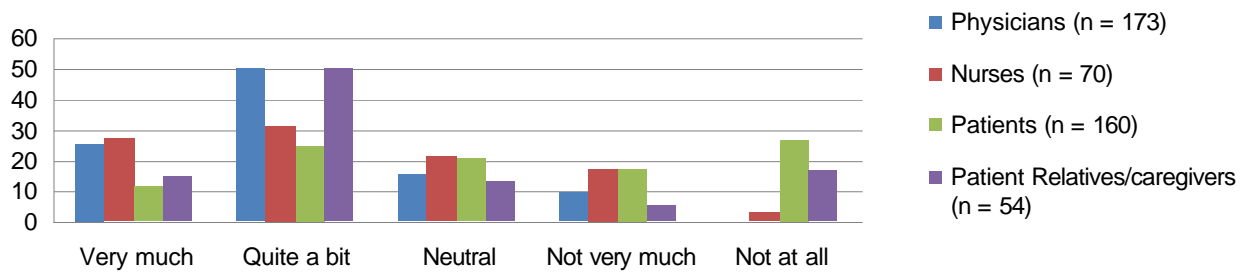
Graph 15a) Peripheral Neuropathy makes it difficult to cope with myeloma (in %)

## 8.2) Peripheral Neuropathy makes it difficult to correctly follow the treatment plan (in %)



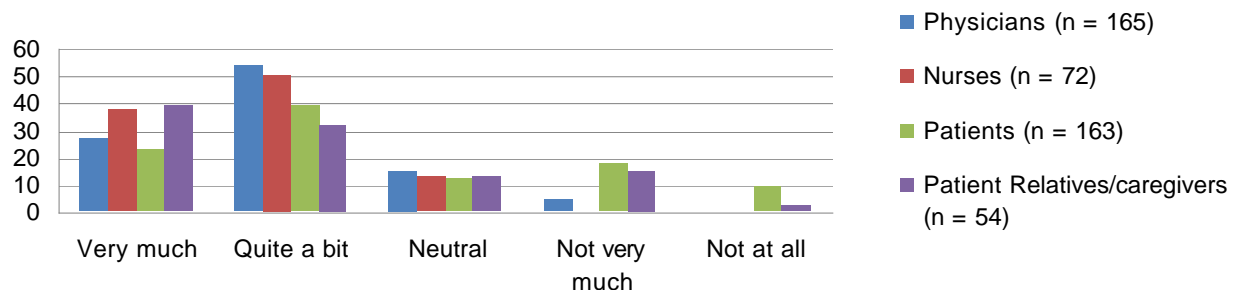
Graph 15b) Peripheral Neuropathy makes it difficult to correctly follow the treatment plan (in %)

## 8.3) Peripheral Neuropathy makes it difficult to stay on myeloma treatment (in %)



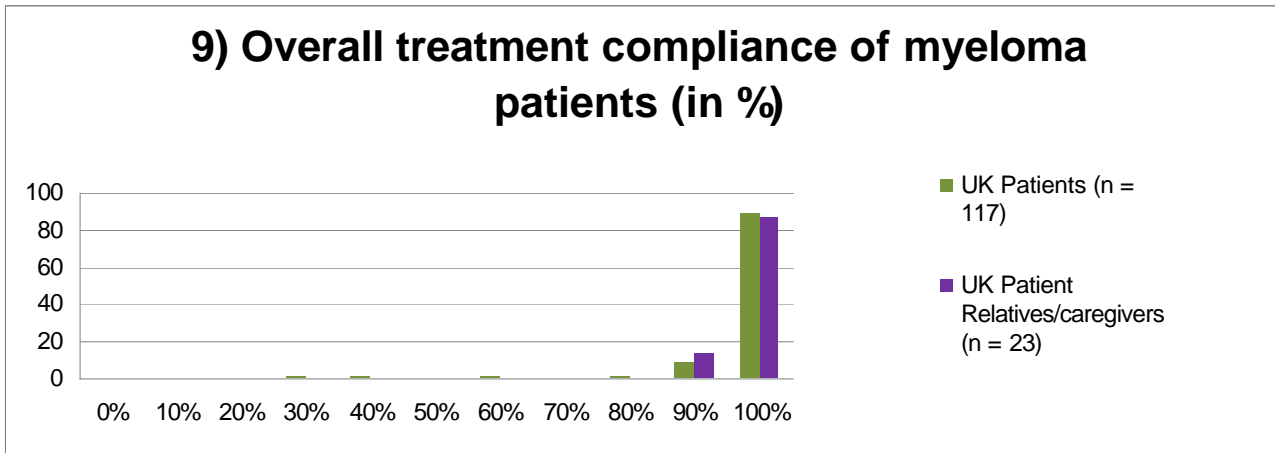
Graph 15c) Peripheral Neuropathy makes it difficult to stay on myeloma treatment (in %)

## 8.4) Peripheral Neuropathy makes it difficult to carry on with daily activities (in %)

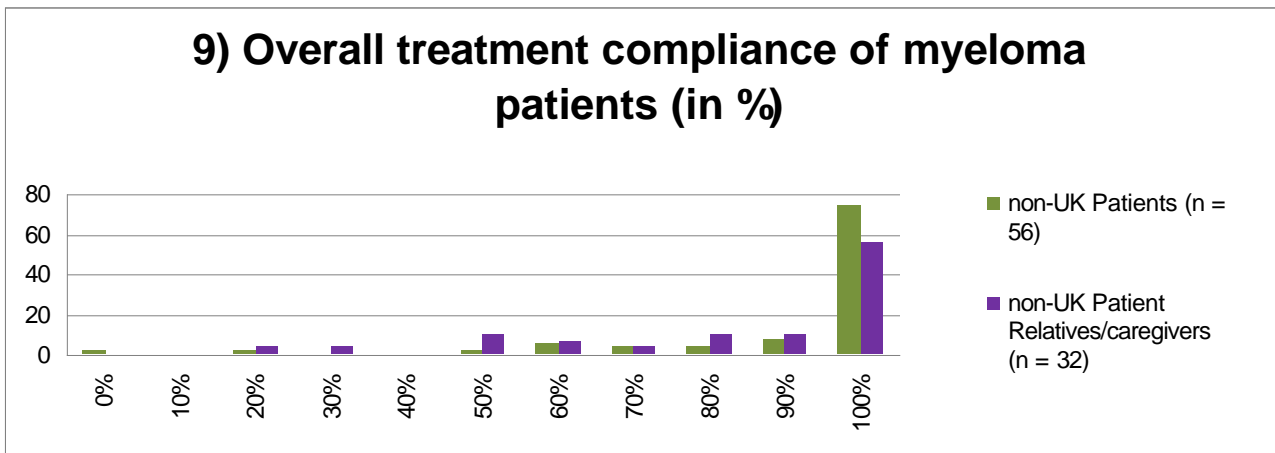


Graph 15d) Peripheral Neuropathy makes it difficult to carry on with daily activities (in %)

**Question 9 for patients/patient relatives/caregivers**



Graph 16a) Overall treatment compliance of myeloma patients as indicated by UK patients, patient relatives and caregivers (in %)



Graph 16b) Overall treatment compliance of myeloma patients as indicated by non-UK patients, patient relatives and caregivers (in %)