

Myeloma Euronet
INTERNATIONAL SURVEY – BARRIERS TO MYELOMA
DIAGNOSIS, TREATMENT, AND CARE 2006
S U M M A R Y R E P O R T

Myeloma Euronet is the European Network of Myeloma Patient Groups whose mission is to raise awareness and provide information on the diagnosis, treatment and care of persons living with multiple myeloma as well as support for their families and loved ones.

Purpose: This quantitative, cross-sectional, descriptive survey was designed to take a look at existing barriers to myeloma diagnosis, treatment, and care through obtaining comparative data about the opinions of several parties involved, with a special focus on physicians and patients and patient relatives. Survey results will be used to help raise awareness about the state and importance of adequate myeloma diagnosis, treatment and care and to encourage national and international health care leaders and political decision-makers to focus greater attention on the appropriate diagnosis, treatment and care for myeloma patients in Europe.

Methods: Data was collected during the 11th Congress of the European Hematology Association in Amsterdam, The Netherlands (15-18 June 2006) and at the 5th ESMO Patient Seminar in Istanbul, Turkey (30 September - 1 October 2006) as well as at local educational meetings of the Austrian and German Myeloma Euronet member organisations and through the network's Web site at www.myeloma-euronet.org (23 May - 23 October 2006) by a self-administered questionnaire including three multiple-choice and two open questions/sub questions that took about 5-10 minutes to complete. Quantitative data analysis and evaluation was structured by questions and groups of participants which were subdivided into physicians and patients and relatives and further subdivided by country. Only groups with five or more individuals were included in the evaluation graphs.

Groups of participants: In all, 163 individuals from 42 countries have participated in the survey. 49% of participants were male, 51% female; 85% came from Europe, 6% from Asia; 5% from Africa; 2% from the United States of America; 1% from South America; and 1% from Australia. 26% of participants were patients or patient relatives (from 10 countries; 93% from Europe); 58% physicians (77% of whom were haematologists; 82% from Europe); 7% representatives from cancer support and advocacy organizations; 6% representatives from the pharmaceutical industry; and 3% others.

SUMMARY OF RESULTS

Introductory remark

Because of the comparatively small number survey participants, this survey cannot be considered as representative for the thoughts and opinions of myeloma patients and physicians across Europe. The uneven distribution of participant groups from individual countries also does not allow comparing opinions expressed by physicians 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 on one side and patients/relatives on the other side, especially in cases where thoughts and opinions are shared or reveal significant differences.

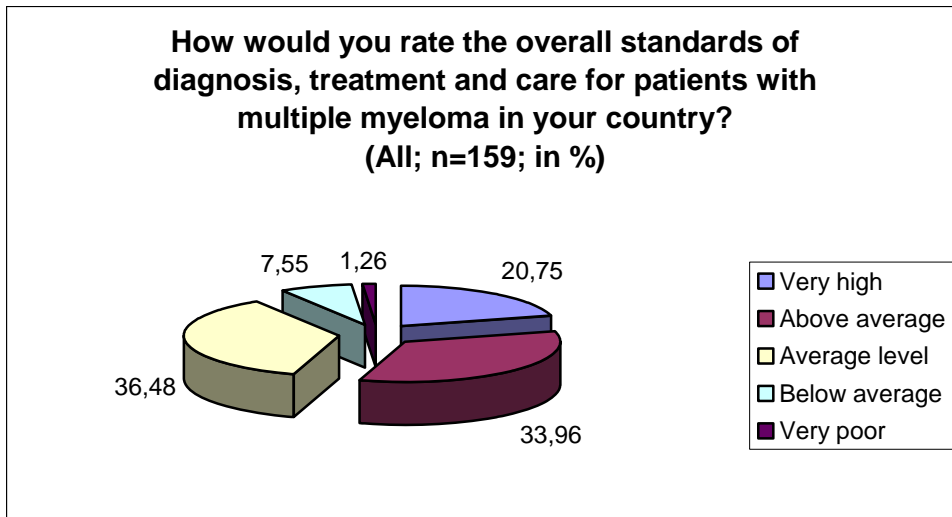
Question 1

“On an international scale, how would you rate the overall standards of diagnosis, treatment and care for patients with multiple myeloma in your country?”
(1 = very high; 2 = above average; 3 = average level; 4 = below average; 5 = very poor)

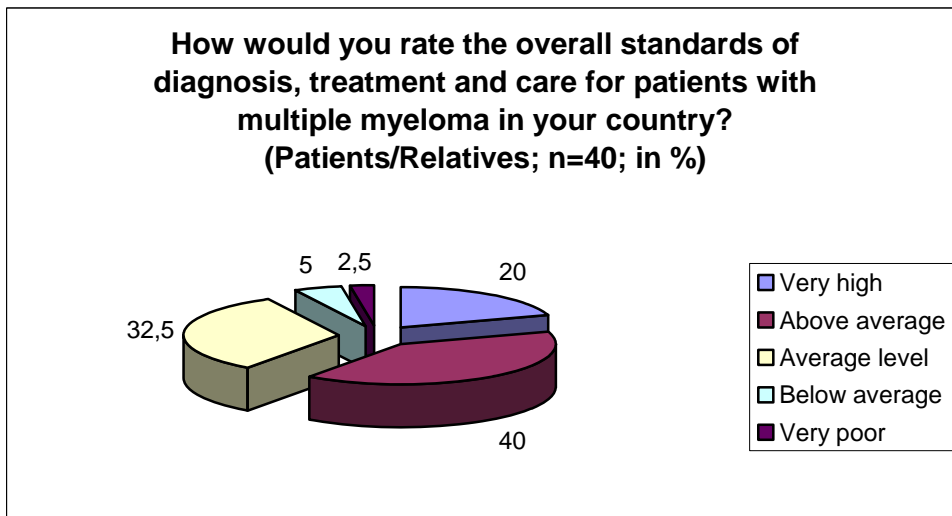
The majority of survey participants (55%) rated the standards of myeloma diagnosis, treatment and care in their countries very high or above average. About one in ten participants (9%) said those standards were below average or very poor in their respective countries. The highest ratings were given by partici-

participants from the Czech Republic and Italy (>80% very high or above average), and the lowest by participants from France (25% below average).

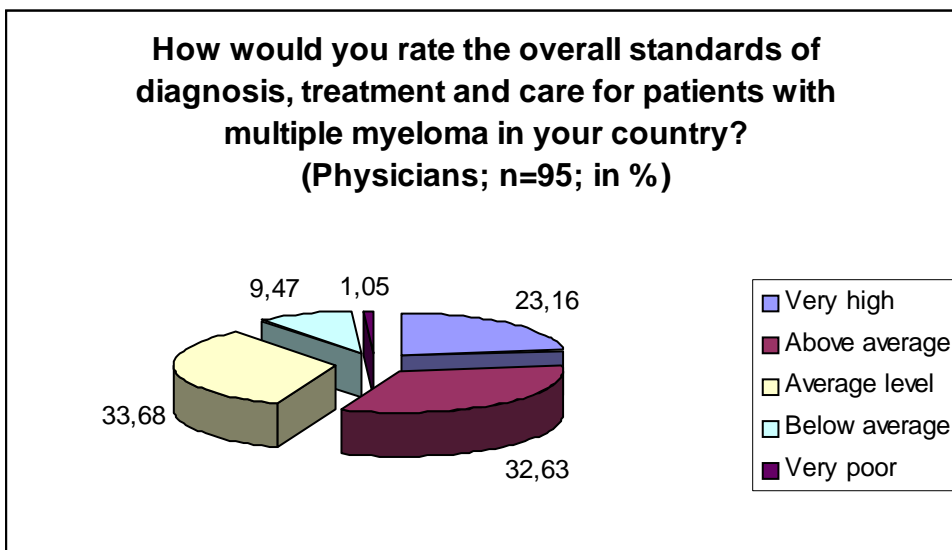
The ratings given by patients and relatives were slightly higher than those given by physicians, with the highest ratings given by physicians from Italy and Spain (>80% very high or above average), and the lowest by patients from France and the United Kingdom (>15% below average).



Graph 1



Graph 2



Graph 3

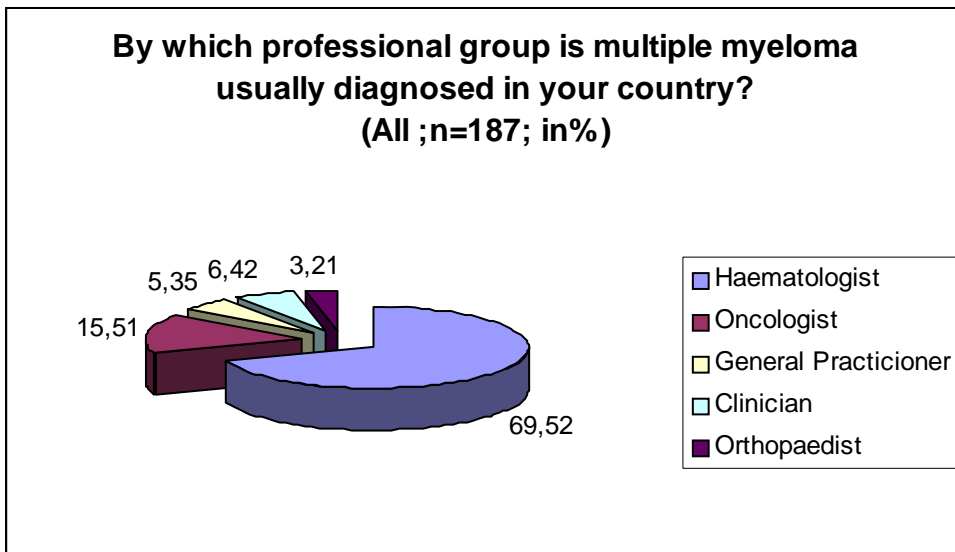
Graphs 1-3: Overall standards of diagnosis, treatment and care for patients with multiple myeloma in your country (see page 13 for additional graph)

Question2:

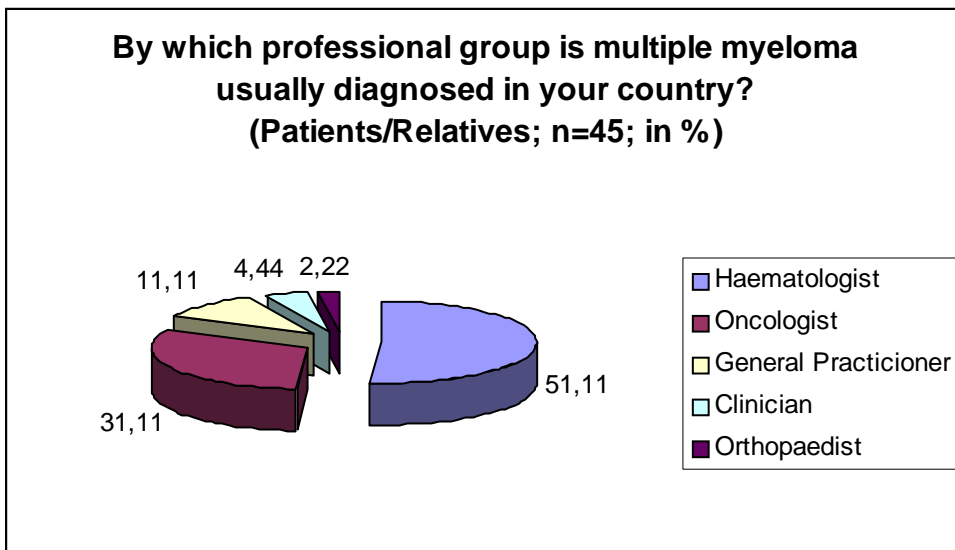
“By which professional group is multiple myeloma usually diagnosed in your country?”

More than two-thirds of survey participants (70%) stated that multiple myeloma is usually diagnosed by haematologists in their countries. While more than three-quarters of physicians (77%) shared this point of view, it was confirmed by only half of the patients and relatives participating in the survey (51%). Almost one-third of patients and relatives (31%) said that usually oncologists diagnose myeloma in their countries, and almost one fifth (18%) said that diagnosis in their countries is usually done by General Practitioners, clinicians or orthopaedists.

For Austria and Germany, the difference was even more significant: Around 60% of Austrian and 50% of German patients and relatives claimed that myeloma diagnosis is usually done either by an oncologist (42% and 25% respectively) or by a General Practitioner, clinician or orthopaedist (16%/25%).

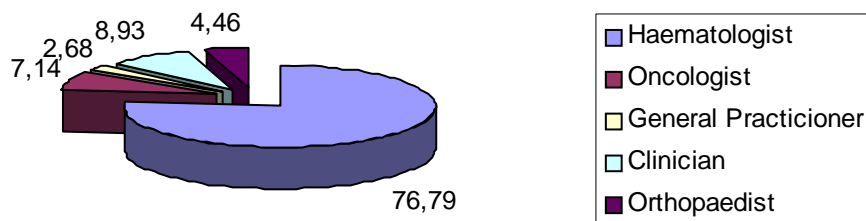


Graph 4



Graph 5

**By which professional group is multiple myeloma usually diagnosed in your country?
(Physicians; n=112; in %)**



Graph 6

Graphs 4-6: Professional group usually diagnosing multiple myeloma in your country (see page 14 for additional graph)

Question 3:

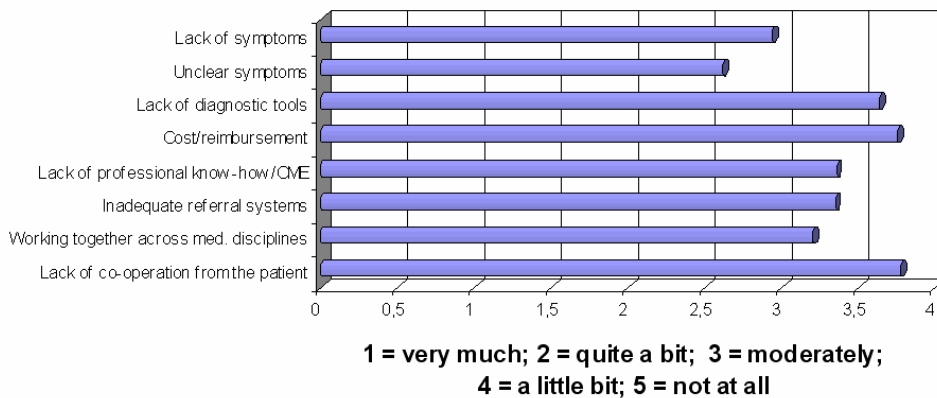
“To what extent would you say the following issues constitute a barrier to the diagnosis of multiple myeloma in your country?”

(1 = very much; 2 = quite a bit; 3 = moderately; 4 = a little bit; 5 = not at all)

Overall, survey participants agreed that unclear symptoms constitute the greatest barrier to myeloma diagnosis in their countries (average value 2.6), followed by lack of symptoms (2.9), working together across medical disciplines (3.2), inadequate referral systems (3.4), and lack of professional know-how/CME (3.4). Patients and relatives considered the lack of professional know-how/CME a slightly bigger barrier to myeloma diagnosis than physicians (3.0 vs. 3.5).

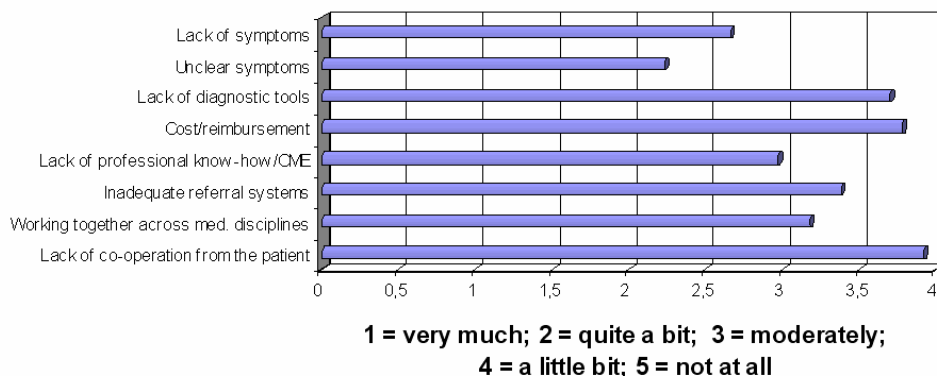
On average, lack of diagnostic tools (3.6), cost/reimbursement of diagnostic procedures (3.8) and lack of co-operation from the patient (3.8) were considered less significant barriers to myeloma diagnosis.

**To what extent would you say the following issues constitute a barrier to the diagnosis of multiple myeloma in your country?
(All; n=158)**



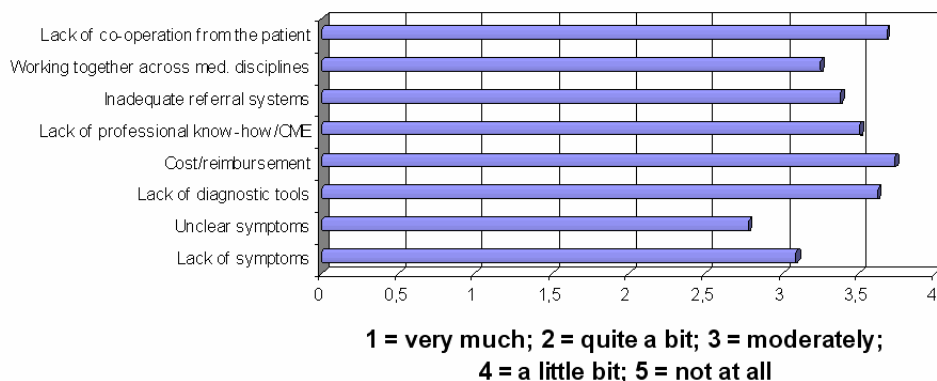
Graph 7

**To what extent would you say the following issues constitute a barrier to the diagnosis of multiple myeloma in your country?
(Patients/Relatives; n=40)**



Graph 8

**To what extent would you say the following issues constitute a barrier to the diagnosis of multiple myeloma in your country?
(Physicians; n=93)**



Graph 9

Graphs 7-9: Barriers to myeloma diagnosis in your country
(see page 15 for additional graph)

Question 4:

“In your opinion, what are the three most important steps that should be taken to overcome those barriers to the diagnosis of multiple myeloma in your country?”

Question 4 was an open question and did not provide survey participants with an opportunity to choose from a prepared set of answers but encouraged them to express their own thoughts and ideas. Some survey participants chose not to answer this question, whereas others took the opportunity to state more than three steps for overcoming barriers to myeloma diagnosis.

All 270 answers given in response to this question were counted by using the following set of keyword categories into which all answers were divided:

- Education and information of healthcare professionals (incl. General Practitioners)
- Education and information of General Practitioners
- Education and information of patients

- Education and information in general
- Referral system
- Interdisciplinary co-operation/Networking among healthcare professionals
- Public information/awareness
- Patient awareness
- Physician awareness
- Access to treatment options
- Availability and use of diagnostic tools/facilities
- Cost/money

The seven most frequent categories were included in this survey evaluation.

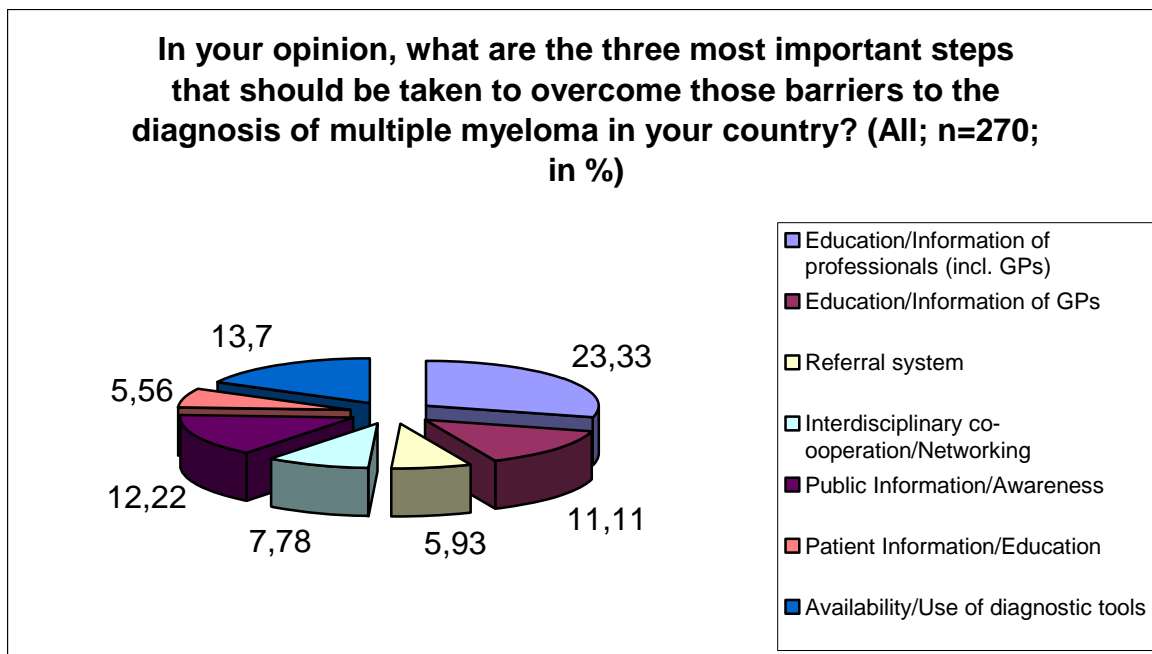
Survey participants found education and information of healthcare professionals (including General Practitioners) to be the most important step to be taken to overcome existing barriers to the diagnosis of multiple myeloma in their respective countries: Almost one-quarter of all participants and the same percentage of physicians (23% each) and 15% of patients and relatives shared this point of view.

About one in ten survey participants (11% of all participants, 9% of patients and relatives, and 10% of physicians) supported the idea of increasing the level of education and information of General Practitioners in particular.

Making sure that relevant diagnostic tools and facilities are made available and are being used by physicians was considered to be the second-most important step to bring down the barriers to myeloma diagnosis: 14% of all survey participants, 12% of patients and relatives, and 17% of physicians voted in favour of this approach.

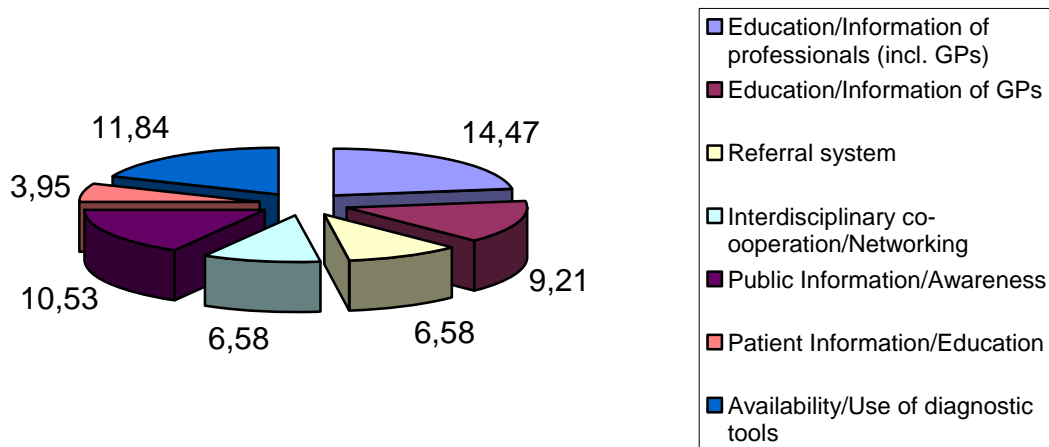
While survey participants in general (12%) and patients and relatives in particular (11%) agreed that increasing the level of public information and awareness is the third-most important step to overcome the barriers to myeloma diagnosis in their countries, 10% of physicians participating in the survey considered interdisciplinary co-operation and networking to be the third step that should be taken to facilitate myeloma diagnosis in their countries.

In contrast to the general opinion expressed in this survey, almost one-third of survey participants from the United Kingdom (30%) said that raising public information and awareness of multiple myeloma is the second-most important step to overcome the barriers to myeloma diagnosis in their country.



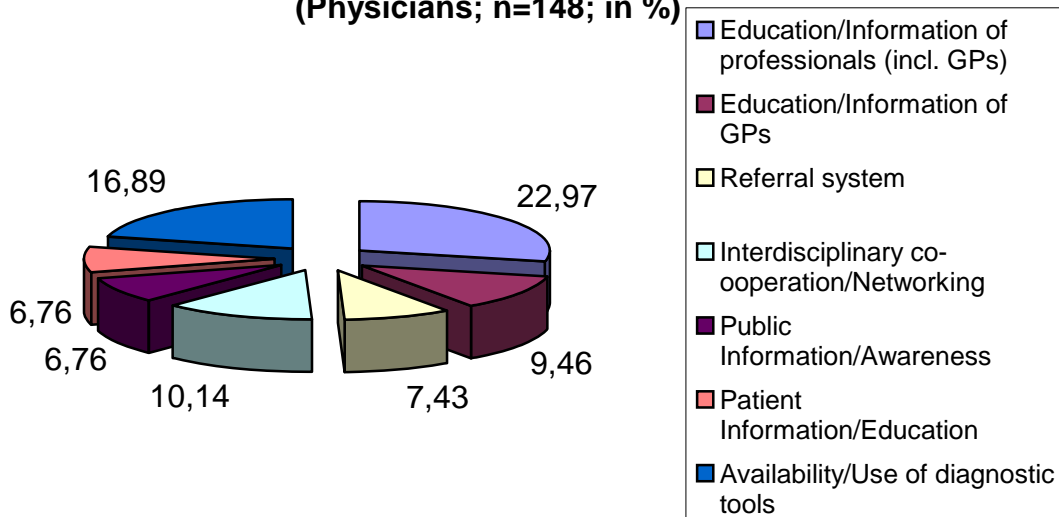
Graph 10

**In your opinion, what are the three most important steps that should be taken to overcome those barriers to the diagnosis of multiple myeloma in your country?
(Patients/Relatives; n=76; in %)**



Graph 11

**In your opinion, what are the three most important steps that should be taken to overcome those barriers to the diagnosis of multiple myeloma in your country?
(Physicians; n=148; in %)**



Graph 12

Graphs 10-12: Most important steps to be taken to overcome barriers to myeloma diagnosis in your country (see page 16 for additional graph)

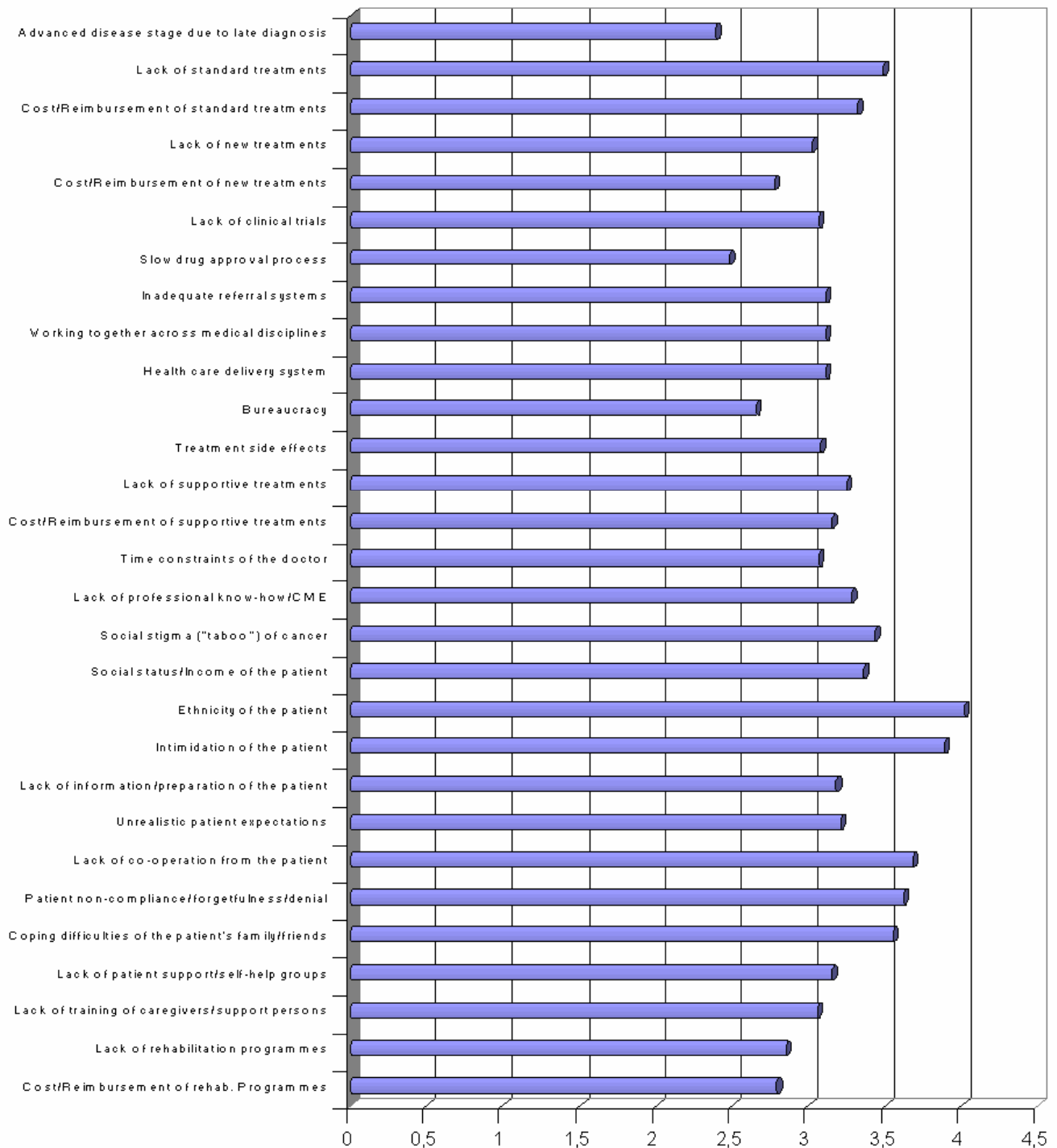
Question 5:

“To what extent would you say the following issues currently constitute a barrier to the treatment and care of myeloma patients in your country?”
(1 = very much; 2 = quite a bit; 3 = moderately; 4 = a little bit; 5 = not at all)

Advanced disease stage due to late diagnosis and the slow drug approval process constitute the two greatest barriers to myeloma treatment and care, according to the participants of this survey (average values 2.4 and 2.5 respectively). This point of view is shared by physicians (same values) as well as by patients and relatives (2.3 and 2.4 respectively) who have participated in this survey.

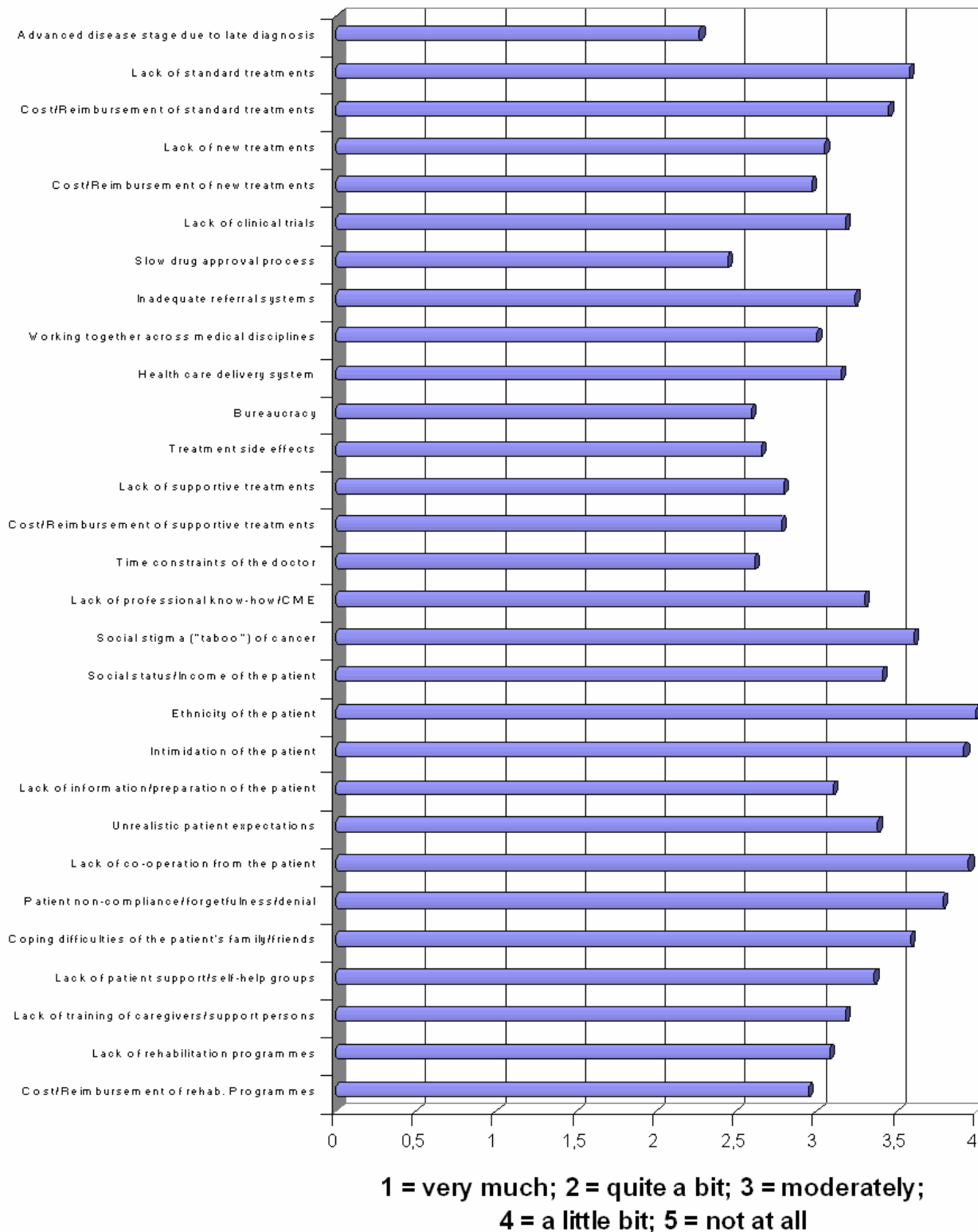
Patient and relatives considered bureaucracy (2.6), time constraints of the doctor (2.6) and treatment side effects (2.7) to be the third-, fourth- fifth-most important barriers to myeloma treatment and care in their countries, whereas physicians felt that those are cost/reimbursement of rehabilitation programmes, bureaucracy, and cost/reimbursement of new treatments (2.6 for all).

**To what extent would you say the following issues currently constitute a barrier to the treatment and care of myeloma patients in your country?
(All; n=157)**



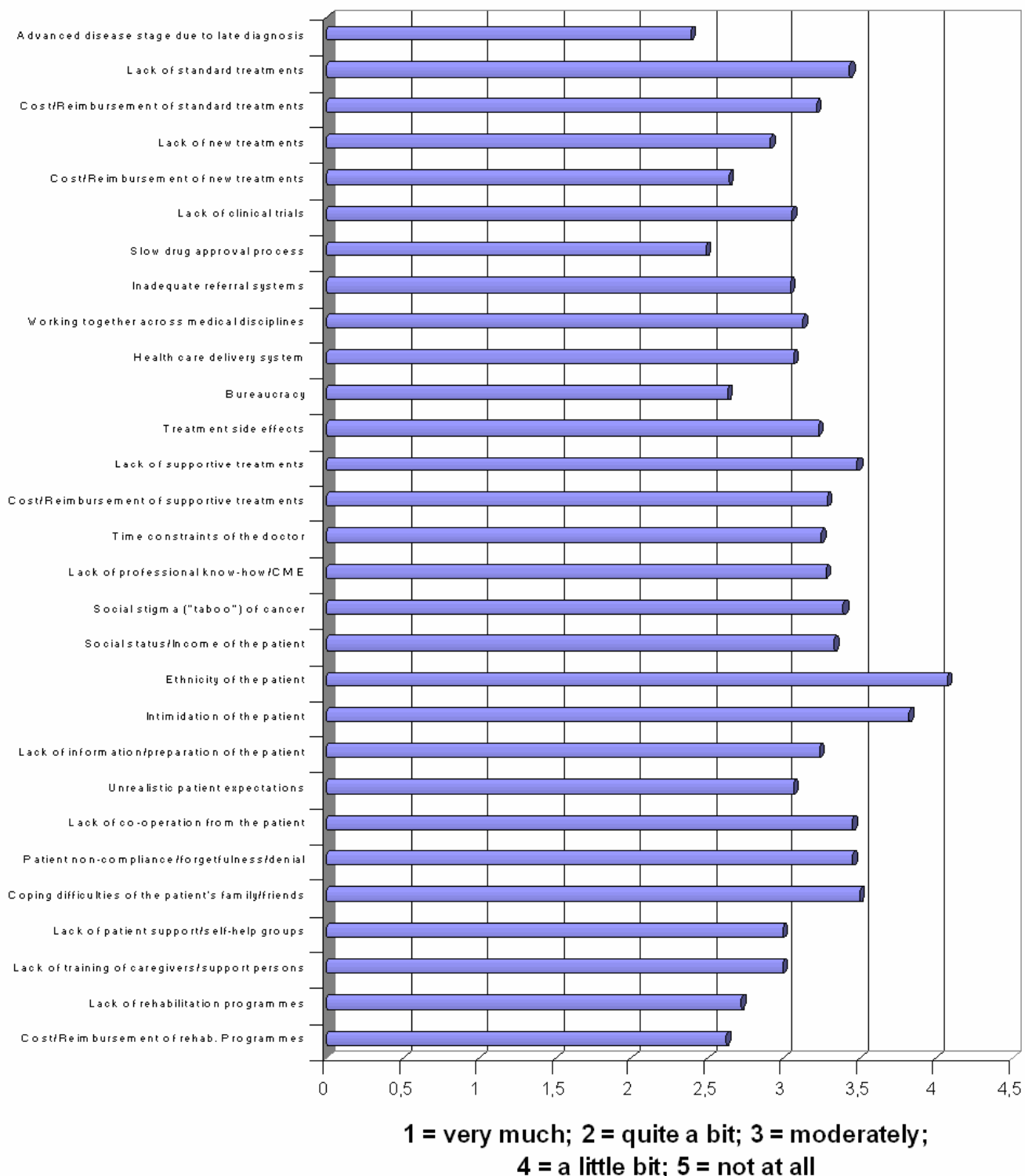
**1 = very much; 2 = quite a bit; 3 = moderately;
4 = a little bit; 5 = not at all**

To what extent would you say the following issues currently constitute a barrier to the treatment and care of myeloma patients in your country? (Patients/Relatives; n=41)



Graph 14

**To what extent would you say the following issues currently constitute a barrier to the treatment and care of myeloma patients in your country?
(Physicians; n=91)**



Graph 15

Graphs 13-15: Barriers to myeloma treatment and care in your country (see page 17 for additional graph)

Question 6:

“In your opinion, what are the three most important steps that should be taken to overcome those barriers to myeloma treatment and care in your country?”

Like question 4, this question was an open question inviting participants to state their own thoughts and ideas rather than choosing from a prepared set of answers. All answers were counted by using the following set of keyword categories into which all 291 answers were divided:

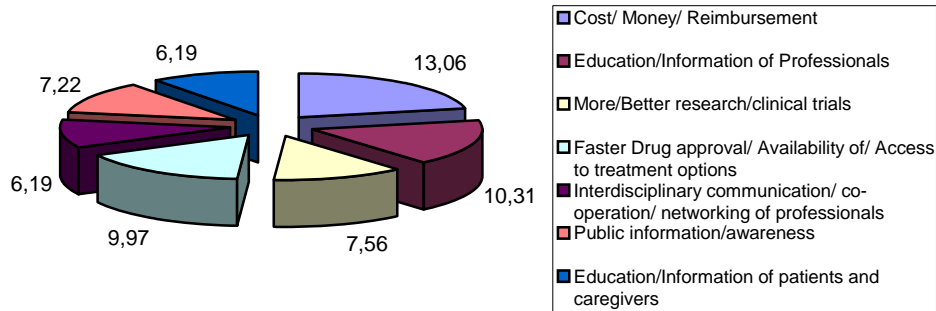
- Cost/money/reimbursement issues
- Education and information of healthcare professionals (incl. General Practitioners)
- More/better research/clinical trials
- Faster drug approval/Availability of, and access to, treatment options
- Interdisciplinary communication/co-operation/Networking of healthcare professionals
- General information/education/Public awareness
- Education and information of patients and caregivers
- More/stronger patient groups/organisations
- Bureaucracy
- Doctor-patient communication/co-operation
- More time
- Change of healthcare system
- Referral system
- Rehabilitation programmes
- More supportive/palliative treatment/care

The seven most frequent categories were included in this survey evaluation.

The majority of physicians participating in the survey stated that the most important step towards overcoming barriers to myeloma treatment and care in their countries is tackling cost, money or reimbursement issues (13%), followed by faster drug approval/availability of, and access to, treatment options (13%) and conducting more and better research and clinical trials (10%). Patients and relatives participating in the survey had a different point of view: Almost one in five patients and relatives (18%) claimed that the first step to be taken should be more education and information of healthcare professionals (incl. General Practitioners), followed by tackling cost, money or reimbursement issues (11%), and providing more education and information for patients and caregivers (9%).

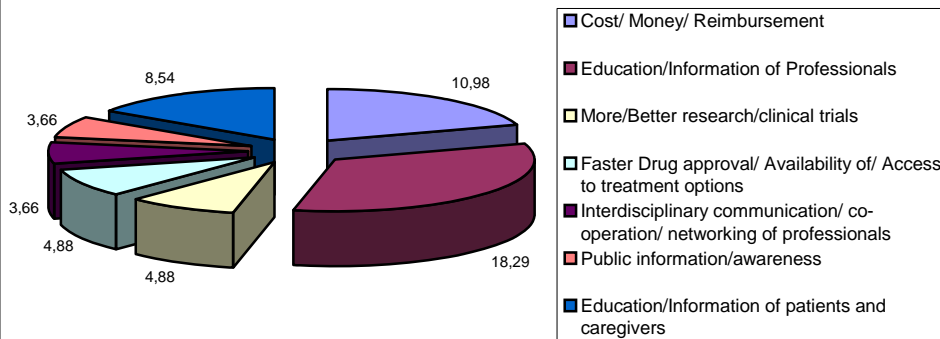
The answers given in response to question 6 vary widely by country. For example, tackling cost and reimbursement issues appears to be of greater importance for physicians from Romania and Serbia, when compared with the opinions expressed by, for example, physicians from Spain and Italy. This suggests that approaches towards improving myeloma treatment and care in Europe have to be taken on a country-by-country basis, taking into consideration the circumstances and requirements in each individual country.

In your opinion, what are the three most important steps that should be taken to overcome those barriers to myeloma treatment and care in your country? (All; n=291; in %)



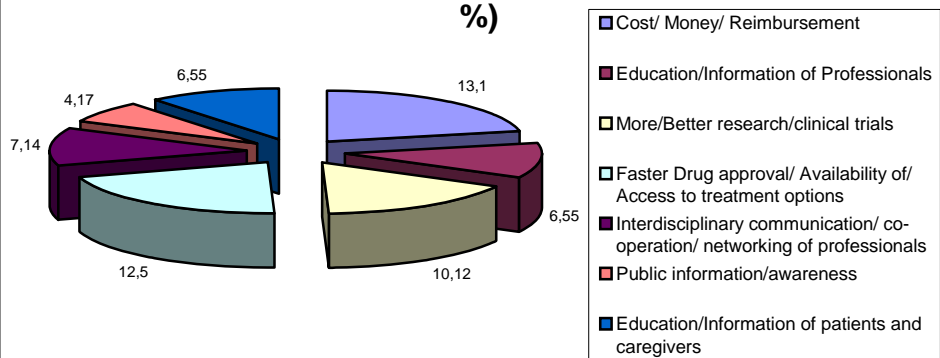
Graph 16

In your opinion, what are the three most important steps that should be taken to overcome those barriers to myeloma treatment and care in your country? (Patients/Relatives; n=82; in %)



Graph 17

In your opinion, what are the three most important steps that should be taken to overcome those barriers to myeloma treatment and care in your country? (Physicians; n=168; in %)

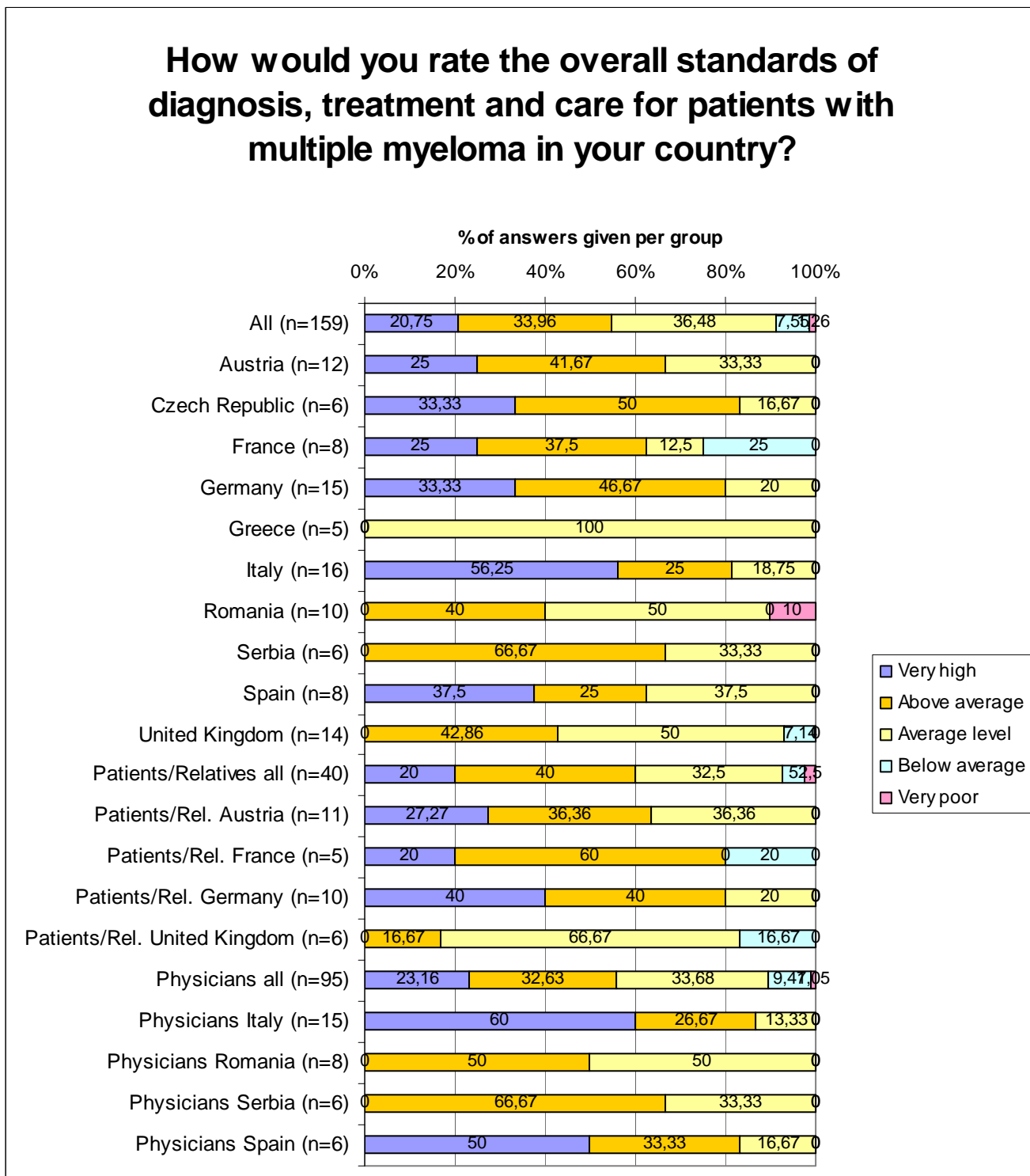


Graph 18

Graphs 16-18: Most important steps to be taken to overcome barriers to myeloma treatment and care in your country (see page 18 for additional graph)

Additional Graphs

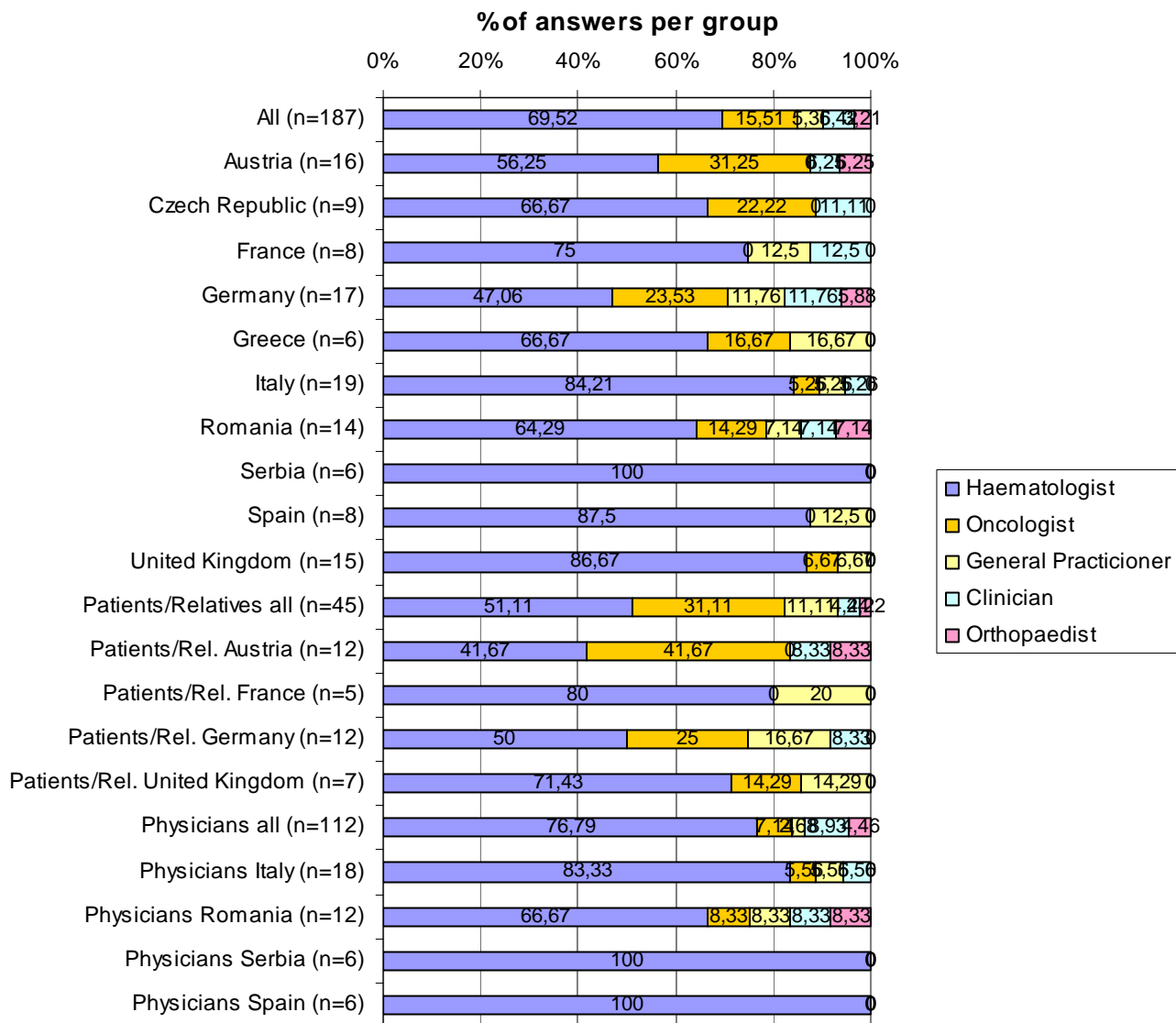
Question 1



Graph 3a: Overall standards of diagnosis, treatment and care for patients with multiple myeloma in your country

Question 2

By which professional group is multiple myeloma usually diagnosed in your country?

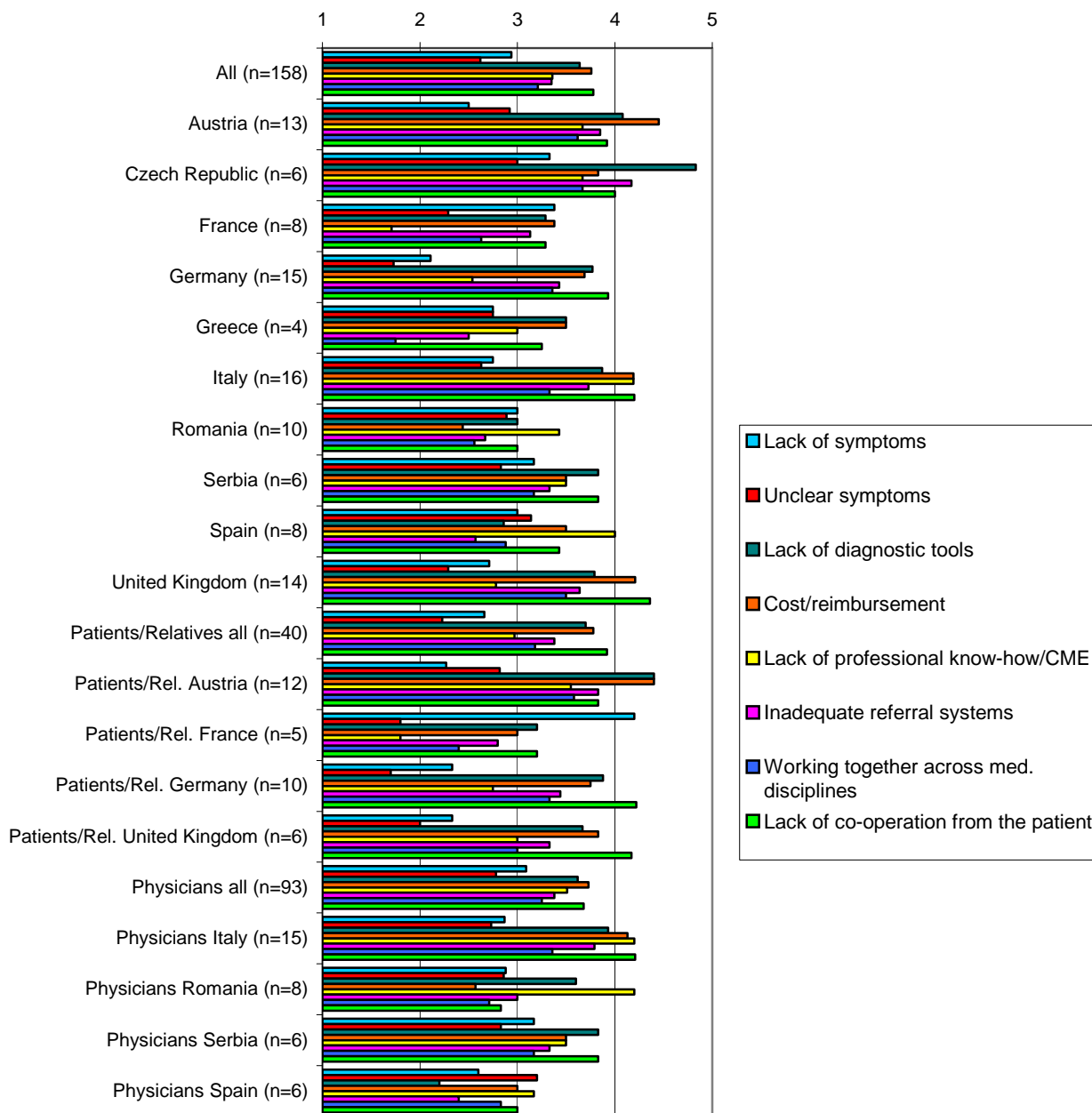


Graph 6a: Professional group usually diagnosing multiple myeloma in your country

Question 3

To what extent would you say the following issues constitute a barrier to the diagnosis of multiple myeloma in your country?

1 = very much; 2 = quite a bit; 3 = moderately; 4 = a little bit; 5 = not at all



Graph 9a: Barriers to myeloma diagnosis in your country

Question 4

What are the three most important steps that should be taken to overcome those barriers to the diagnosis of multiple myeloma in your country?

% of answers given per group
(>100% where more than 1 answer was given per response)

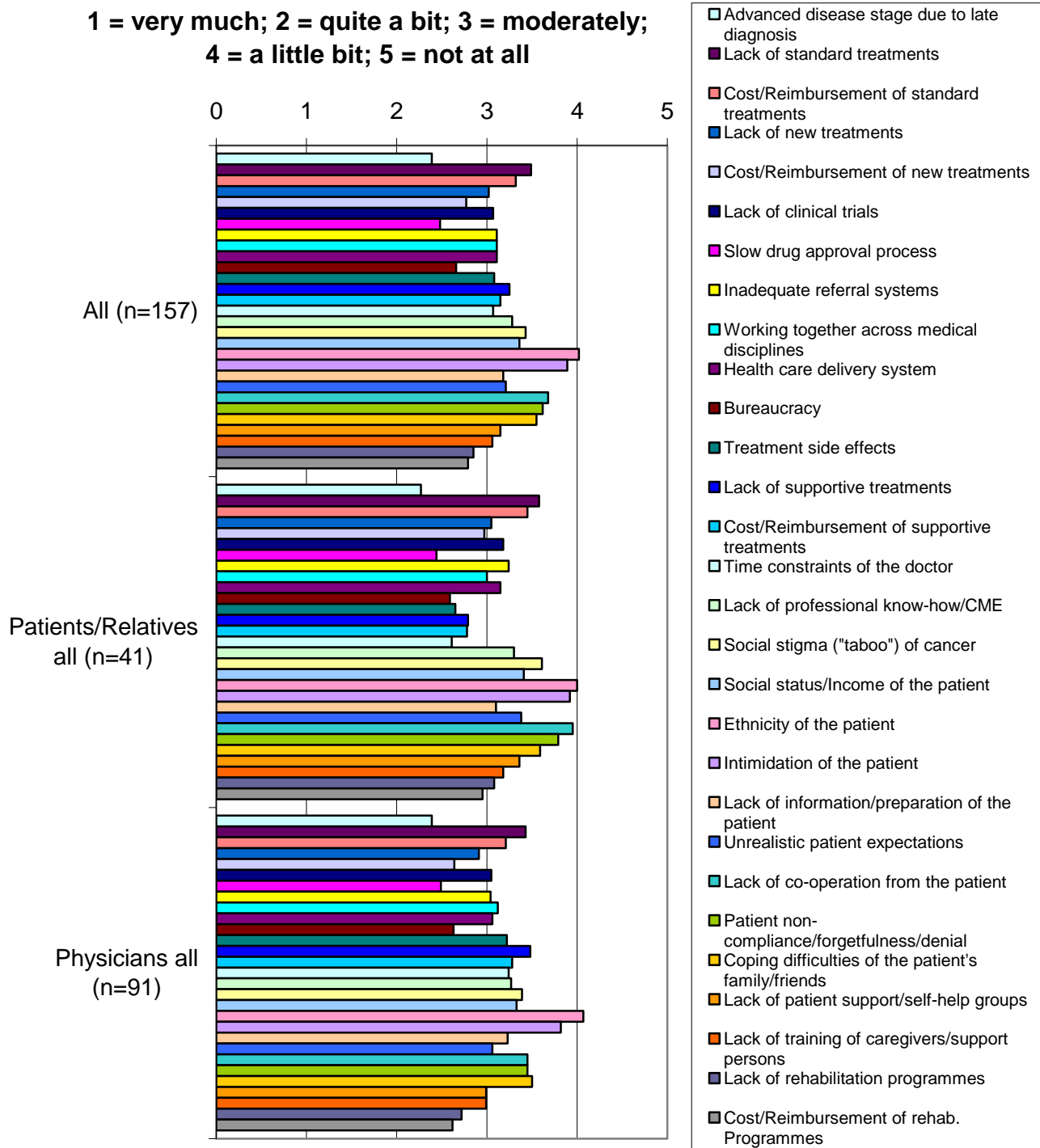


Graph 12a: Most important steps to be taken to overcome barriers to myeloma diagnosis in your country

Question 5

To what extent would you say the following issues currently constitute a barrier to the treatment and care of myeloma patients in your country?

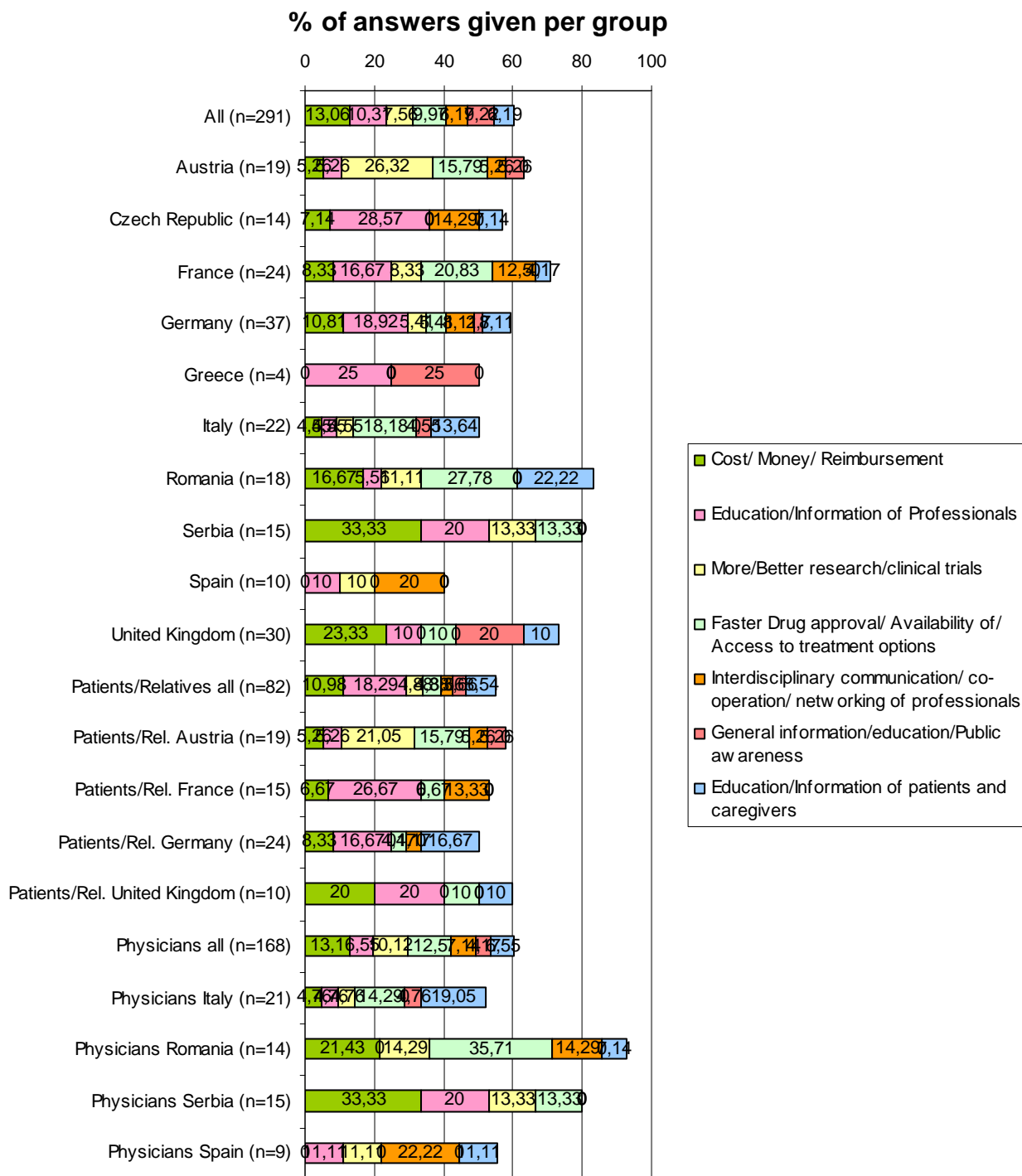
1 = very much; 2 = quite a bit; 3 = moderately; 4 = a little bit; 5 = not at all



Graph 15a: Barriers to myeloma treatment and care in your country

Question 6

What are the three most important steps that should be taken to overcome those barriers to myeloma treatment and care in your country?



Graph 18a: Most important steps to be taken to overcome barriers to myeloma treatment and care in your country