



MYELOMA
EURONET

Myeloma Euronet INTERNATIONAL SURVEY – DETECTING MYELOMA 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 obtain more information from physicians and patients about the path patients take to myeloma diagnosis, what medical professionals from different non-haematological and non-oncological medical specialties do to detect myeloma, how much time passes from initial consultation to myeloma diagnosis, and what should be done to avoid delays in myeloma diagnosis. 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 detection.

Methods: The survey was conducted between June and December 2009 during two international medical congresses, namely the 10th Congress of the European Federation of National Associations of Orthopaedics and Traumatology (EFORT) in Vienna, Austria (3-6 June 2009) and the 15th European Conference of the World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians (WONCA) in Basel, Switzerland (16-19 September 2009) and via postal questionnaire distribution through, and at local educational meetings of, Myeloma Euronet's member organisations. The patient survey was also available for online participation at the network's Web site, www.myeloma-euronet.org, from 8 July - 31 December 2009. The survey consisted of a self-administered questionnaire with ten questions (nine questions for patients and patient relatives) 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 (two groups of physicians) and myeloma patients and patient relatives.

Groups of participants: In all, 303 physicians from 56 countries (277 or 91.4% from European countries) and 349 myeloma patients and patient relatives from 37 countries of treatment (315 or 90.3% from European countries) have participated in the survey.

Physicians were subdivided into 90 general practitioners and family doctors (29.7%) from 27 countries, 206 orthopaedic surgeons and traumatologists (68.0%) from 47 countries, and 7 physicians from other specialties (not included in the evaluation). More than 90% of the general practitioners and family doctors (92.2%) and almost 95% of the orthopaedic surgeons and traumatologists (94.7%) were between 30 and 69 years of age. Of the general practitioners and family doctors, 45 were male (50%) and 44 female (48.9%). Of the orthopaedic surgeons and traumatologists, 183 were male (88.8%) and 14 female (6.8%). 10 physicians did not indicate their gender.

Survey participants representing patient views were subdivided into 239 myeloma patients (68.5%) from 24 countries of treatment and 110 myeloma patient relatives (31.5%) who participated on behalf of myeloma patients from 31 countries of treatment. Of the myeloma patients represented in the survey, 50 (14.3%) were below 50 years of age, 91 (26.1%) were between 50 and 59 years, and 202 (57.9%) were 60 years and above. 6 patients (1.7%) did not indicate their age. Slightly more than half of the patients were male (181 or 51.9%) and 159 were female (45.6%). 9 patients (2.6%) did not indicate their gender.

It should be noted that the opinions expressed by myeloma patients and patient relatives may include a potential bias, as 105 participants (30.1%) were from the United Kingdom, 87 patients (36.4%) and 18 patient relatives (16.4%). For this reason, responses to all survey questions were also checked for potential significant differences between answers given by myeloma patients and patient relatives from the UK and those given by myeloma patients and patient relatives from other countries.

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 with those of patients and relatives from one and the same country

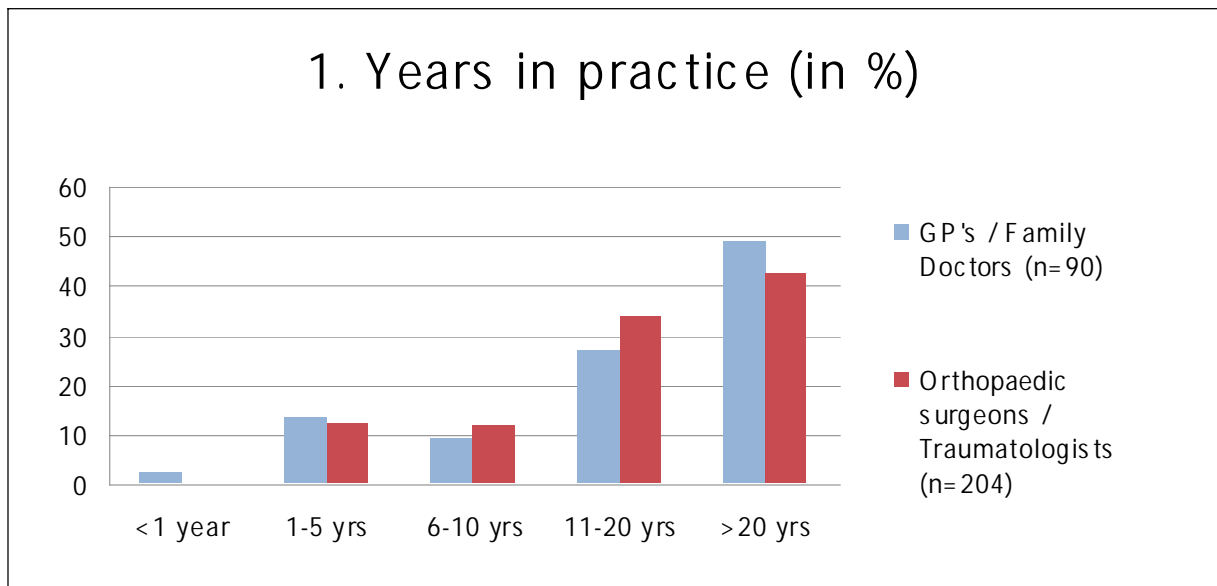
However, this survey does allow drawing some conclusions regarding the thoughts and opinions expressed by physicians on one side and myeloma patients and patient relatives on the other side, especially in cases where thoughts and opinions are shared or reveal significant differences.

Question 1 for physicians:

“For how long have you been practicing in your medical specialty?”

(1) = Less than 1 year; 2) = 1-5 years; 3) = 6-10 years; 4) = 11-20 years; 5) = More than 20 years)

The majority of general practitioners and family doctors (84.5%) and orthopaedic surgeons and traumatologists (87.7%) who have responded to this question stated that they had been practicing in their respective medical specialty for more than 5 years.



Graph 1) Years in practice (in %)

Question 1 for myeloma patients/patient relatives:

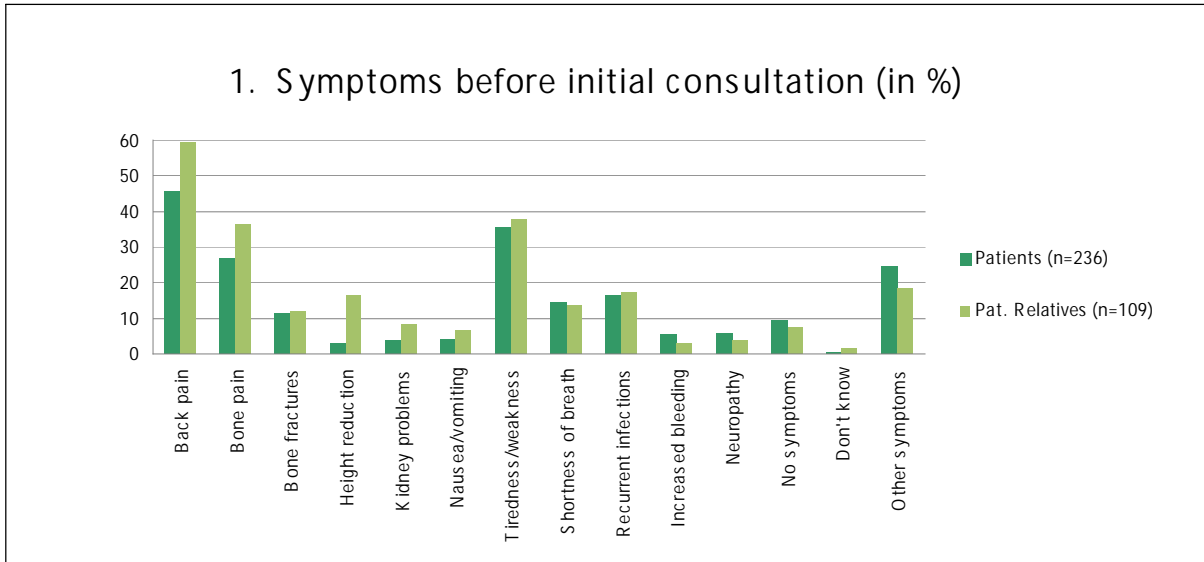
“Initial consultation: Before being diagnosed with myeloma, which was/were the first symptom/s that made you (your family member) see a doctor? Please tick all that apply.”

(1) = Back pain; 2) = Bone pain; 3) = Bone fractures; 4) = Height reduction; 5) = Kidney problems; 6) = Nausea/vomiting; 7) = Tiredness/weakness; 8) = Shortness of breath; 9) = Recurrent infections; 10) Increased bleeding; 11) = Neuropathy (nerve problems); 12) = No symptoms; 13) = Don't know; 14) = Other)

It was possible to tick more than one answer option.

According to myeloma patients and patient relatives who responded to this question, the most frequent symptom experienced before consulting a doctor was back pain (45.8% / 59.6%), followed by tiredness/weakness (35.2% / 37.6%), bone pain (26.7% / 36.7%), recurrent infections (16.5% / 17.4%), shortness of breath (14.4% / 13.8%) and bone fractures (11.4% / 11.9%).

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



Graph 2) Symptoms before initial consultation (in %)

Question 2 for physicians:

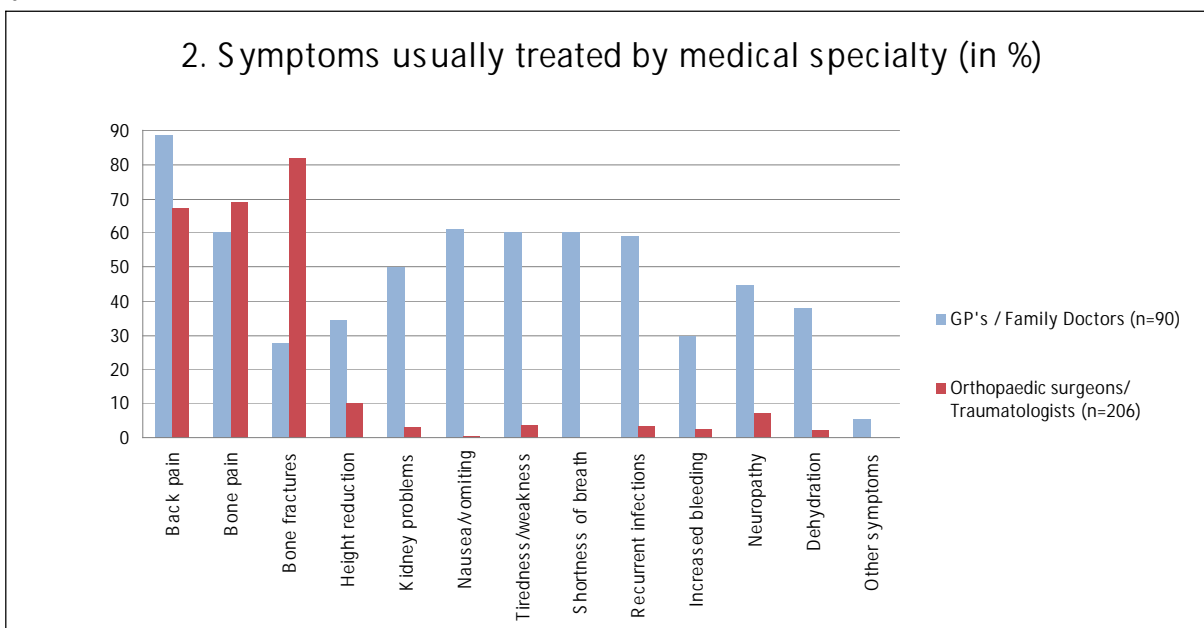
“Which of the following symptoms would usually be treated by your medical specialty?”

(1) = Back pain; 2) = Bone pain; 3) = Bone fractures; 4) = Height reduction; 5) = Kidney problems; 6) = Nausea/vomiting; 7) = Tiredness/weakness; 8) = Shortness of breath; 9) = Recurrent infections (Bacterial pneumonia, urinary tract infections, and shingles); 10) Increased bleeding; 11) = Neuropathy; 12) = Dehydration); 13) = Other)

It was possible to tick more than one answer option.

Of the general practitioners and family doctors who have answered this question, about 9 in 10 (88.9%) said that they usually treat back pain, and more than one in two said that symptoms such as tiredness/weakness (60%), bone pain (60%), recurrent infections (58.9%) and shortness of breath (60%) are also treated by their medical specialty. More than one-quarter of the general practitioners and family doctors (27.8%) answered that they usually also treat bone fractures.

More than two-thirds of orthopaedic surgeons and traumatologists who have responded to this question stated that they usually treat back pain (67.5%), bone pain (68.9%) and bone fractures (82.4%). Symptoms such as tiredness/weakness, recurrent infections or shortness of breath, however, are not among those usually treated by this medical specialty (3.9%, 3.4% and 0% respectively).



Graph 3) Symptoms usually treated by medical specialty (in %)

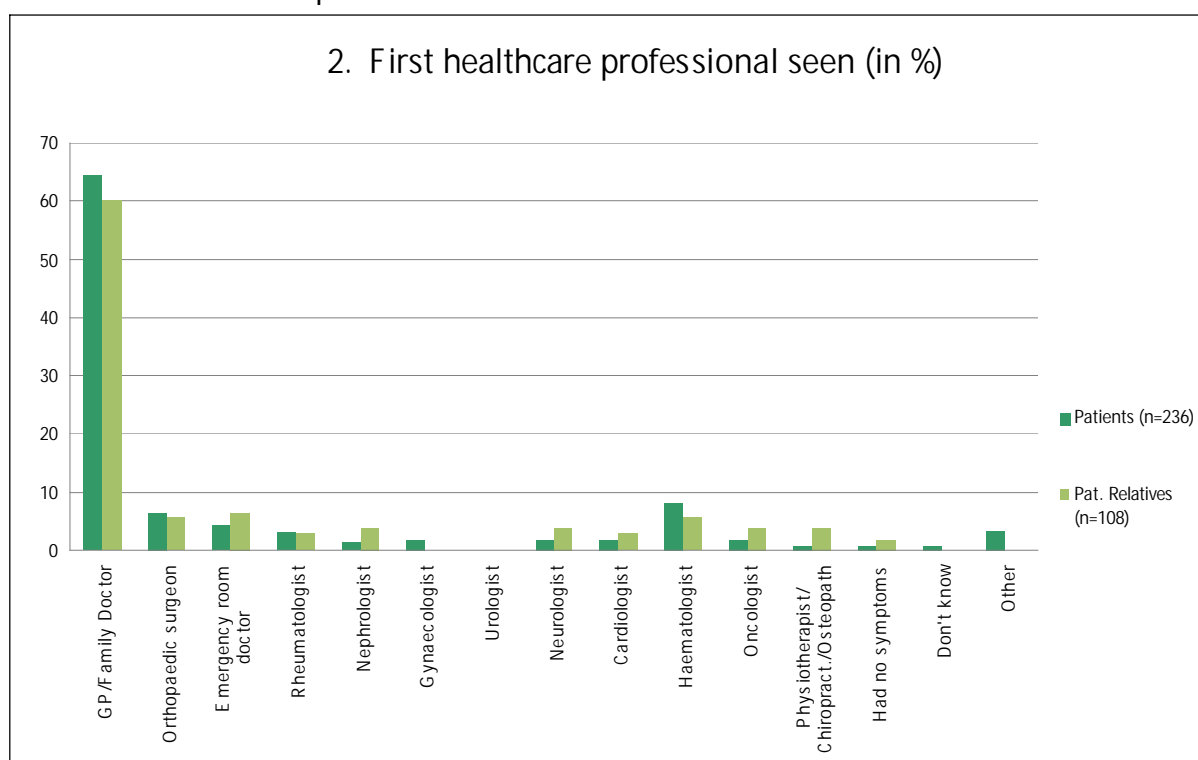
Question 2 for myeloma patients/patient relatives:

”Which of the following was the first healthcare professional you (your family member) saw regarding that/those symptom/s?”

(1) = General Practitioner/Family Doctor; 2) = Orthopaedic Surgeon; 3) = Emergency room doctor; 4) = Rheumatologist; 5) = Nephrologist; 6) = Gynaecologist; 7) = Urologist; 8) = Neurologist; 9) = Cardiologist; 10) = Haematologist; 11) = Oncologist; 12) = Physiotherapist/Chiropractor/Osteopath; 13) = Had no symptoms; 14) = Don't know; 15) = Other)

Because of the symptoms experienced before consulting a doctor, the majority of the myeloma patients (64.4%) and patient relatives (60.2%) who responded to this question stated that the first doctor seen was the general practitioner/family doctor. Only in about 1 in 20 cases (6.4% / 5.6%), the first doctor consulted was an orthopaedic surgeon, and also haematologists are usually not the first medical specialists seen when patients are confronted with myeloma-related symptoms (8.1% / 5.6%).

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



Graph 4) First healthcare professional seen (in %)

Question 3 for physicians:

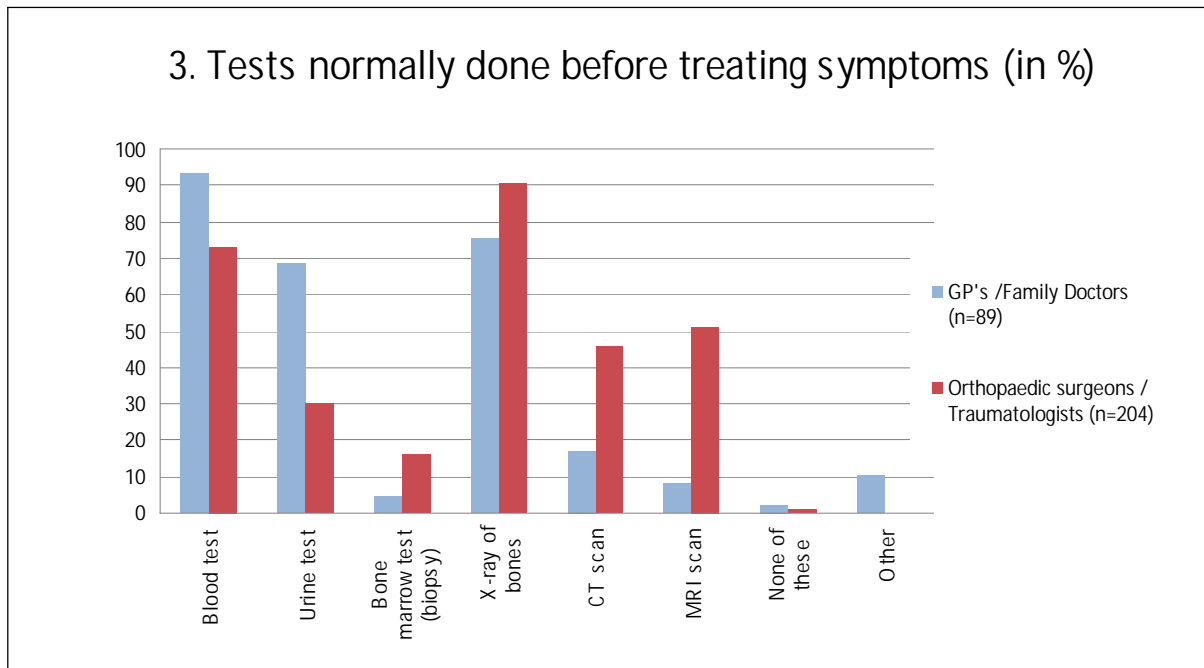
“Before treating the symptoms that you have ticked above, would you normally do any of the following?”

(1) = Blood test; 2) = Urine test; 3) = Bone marrow test (biopsy); 4) = X-ray of bones; 5) = CT scan; 6) = MRI scan; 7) None of these; 8) = Other)

It was possible to tick more than one answer option.

When confronted with the symptoms listed above, more than 9 in 10 general practitioners/family doctors who have answered this question stated that they would normally do a blood test (93.3%), and more than two-thirds of them said that they would do an x-ray of bones (75.3%) or a urine test (68.5%).

More than 9 in 10 orthopaedic surgeons and traumatologists who responded to this question stated that they would x-ray the bones (90.7%), 3 out of 4 would do a blood test (73%), and about one in two would do either a MRI scan (51%) or a CT scan (45.6%).



Graph 5) Tests normally done before treating symptoms (in %)

Question 3 for myeloma patients/patient relatives:

“Following the initial consultation, to which of the following healthcare professionals were you (was your family member) referred? Please tick one box only.”

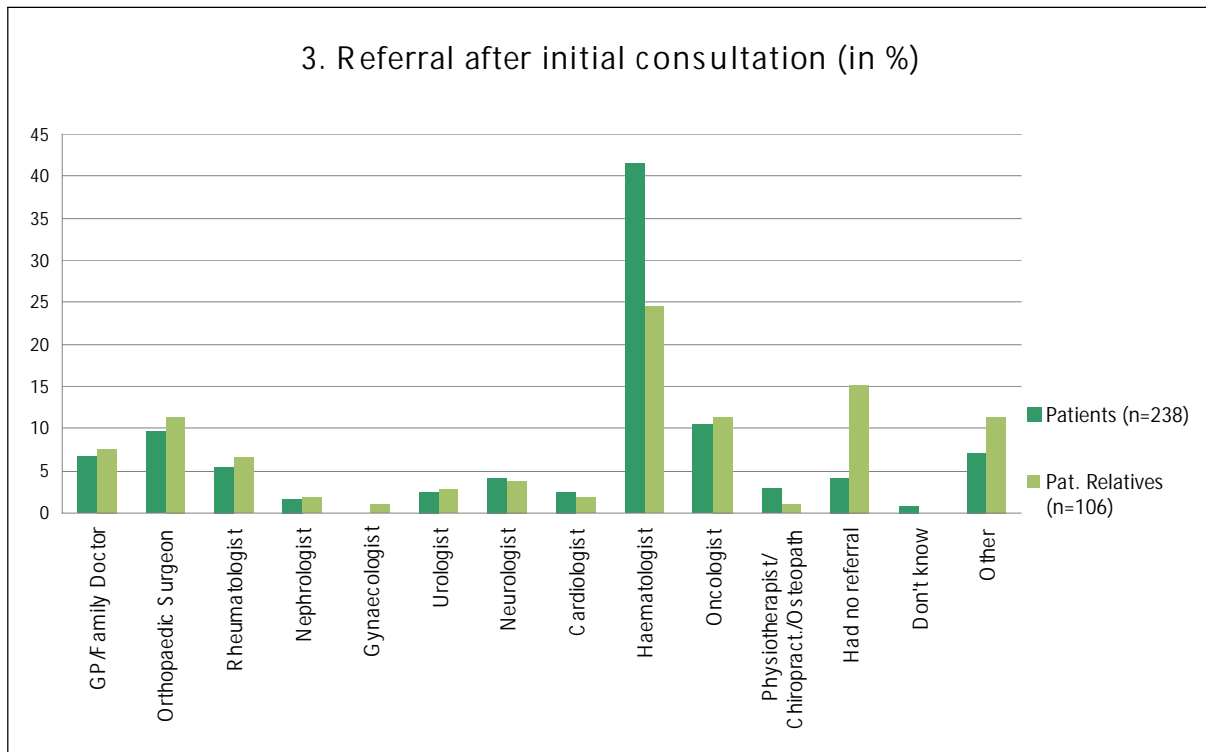
- (1) = General Practitioner/Family Doctor; 2) = Orthopaedic Surgeon; 3) = Rheumatologist;
 4) = Nephrologist; 5) = Gynaecologist; 6) = Urologist; 7) = Neurologist; 8) = Cardiologist;
 9) = Haematologist; 10) = Oncologist; 11) = Physiotherapist/Chiropractor/Osteopath;
 12) = Had no referral; 13) = Don't know; 14) Other)

When asked to which healthcare professionals they (their family members) were referred after the initial consultation, less than half of the myeloma patients (41.6%) and less than one-quarter of the patient relatives (24.5%) who responded to this question said that they/their family members were referred to a haematologist.

The second most frequently mentioned medical specialist in this context was the oncologist (10.5% of myeloma patients / 11.3% of myeloma patients represented by their relatives), followed by the orthopaedic surgeon (9.7% / 11.3%), the general practitioner/family doctor (6.7% / 7.5%) and the rheumatologist (5.5% / 6.6%).

About 1 in 20 myeloma patients (4.2%) and 1 in 7 myeloma patients represented by their relatives stated that they had no referral at all following the initial consultation.

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



Graph 6) Referral after initial consultation (in %)

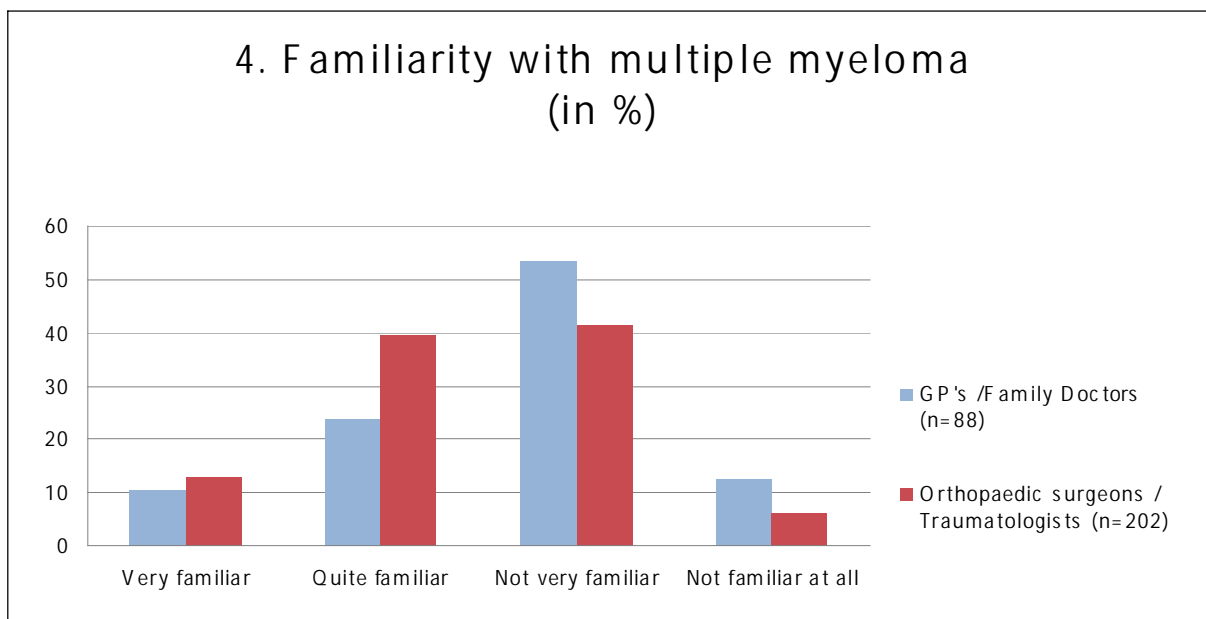
Question 4 for physicians:

“Generally speaking, how familiar would you say you are with multiple myeloma?”

(1) = Very familiar; 2) = Quite familiar; 3) = Not very familiar; 4) Not familiar at all)

When asked about how familiar they felt they were with multiple myeloma, the majority of general practitioners/family doctors and orthopaedic surgeons and traumatologists who responded to this question stated that they were “not very familiar” (53.4% / 41.6%) or “not familiar at all” (12.5% / 5.9%) with this disease.

The survey also revealed that orthopaedic surgeons and traumatologists are more familiar with multiple myeloma than general practitioners/family doctors: About half of the orthopaedic surgeons and traumatologists (52.5%) but only about one-third of the general practitioners/family doctors (34.1%) said that they were either “quite familiar” or “very familiar” with multiple myeloma.



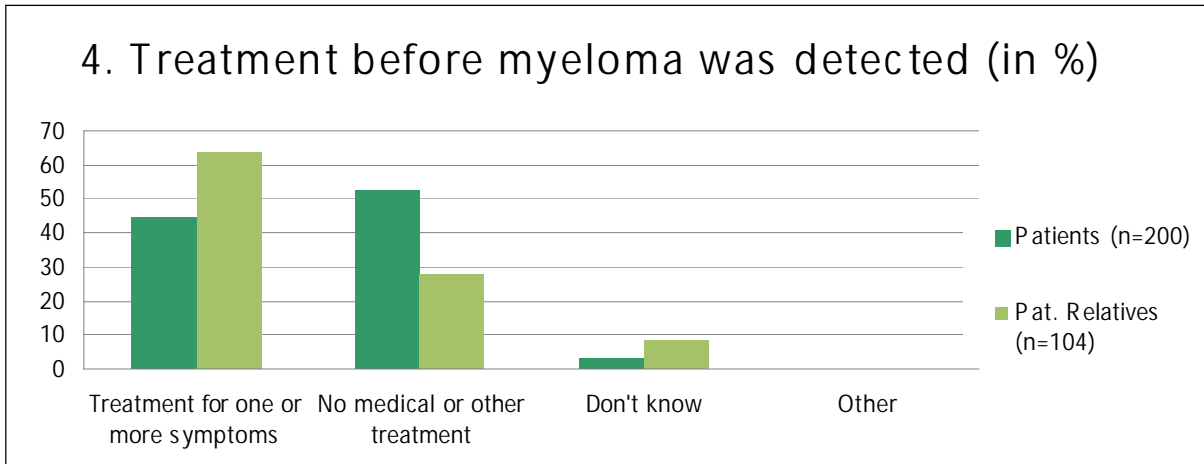
Graph 7) Familiarity with multiple myeloma (in %)

Question 4 for myeloma patients/patient relatives:

”Following the initial consultation, and before the myeloma was detected, did you (your family member) receive any medical or other treatment?”

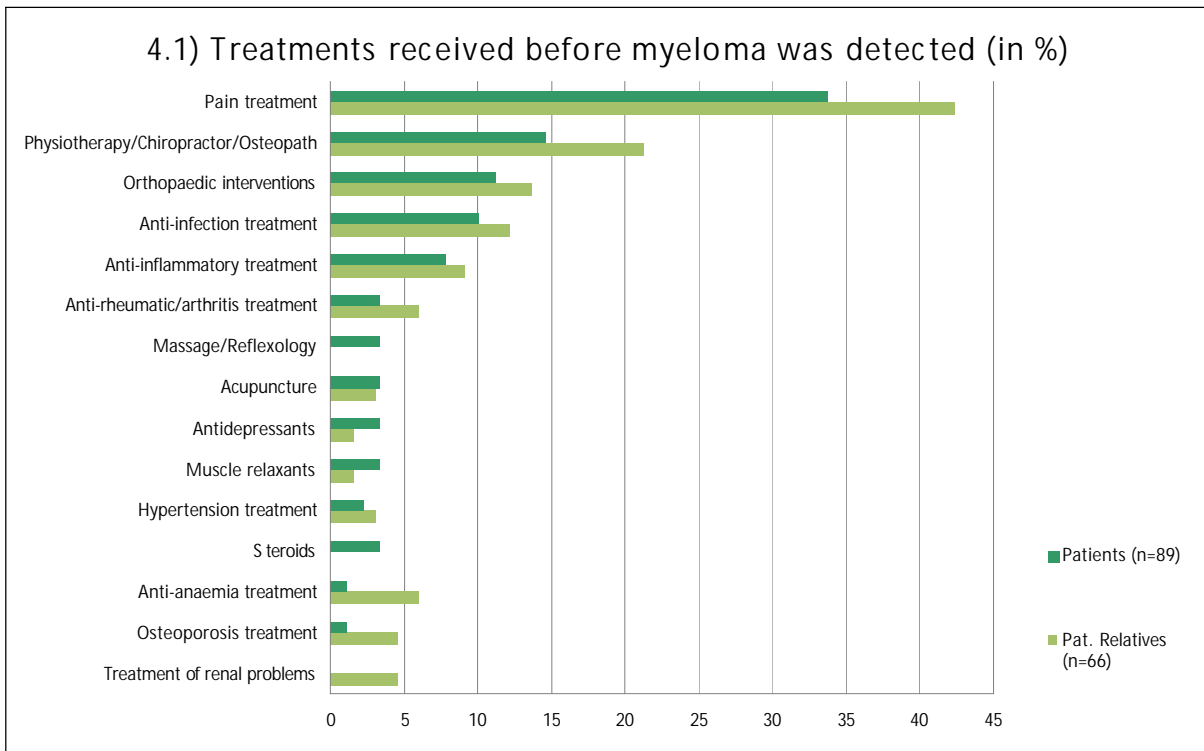
(1) = I (my family member) was treated for one or more of the symptoms stated in question 1: Please specify the treatment/s received:; 2) = Had no medical or other treatment after initial consultation and before the myeloma was detected; 3) = Don't know; 4) = Other)

About half of the myeloma patients (52.5%) and one-quarter of the patients represented by their relatives (27.9%) who responded to this question said that they received no medical or other treatment following the initial consultation, and before the myeloma was detected. On the other hand, close to half of the myeloma patients (44.5%) and close to two-thirds of the patients represented by their relatives (63.5%) replied that they received treatment for one or more symptoms.



Graph 8) Treatment before myeloma was detected (in %)

According to the myeloma patients and patient relatives who also stated the treatments they (their family members) received following the initial consultation, the most frequent treatment was treatment for pain (reported by 33.7% of patients and 42.4% of patient relatives), followed by physiotherapy/chiropractor/osteopath treatment (14.6% / 21.2%), orthopaedic interventions (11.2% / 13.6%), anti-infection treatment (10.1% / 12.1%) and anti-inflammatory treatment (7.9% / 9.1%).



Graph 9) Treatments received before myeloma was detected (in %)

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

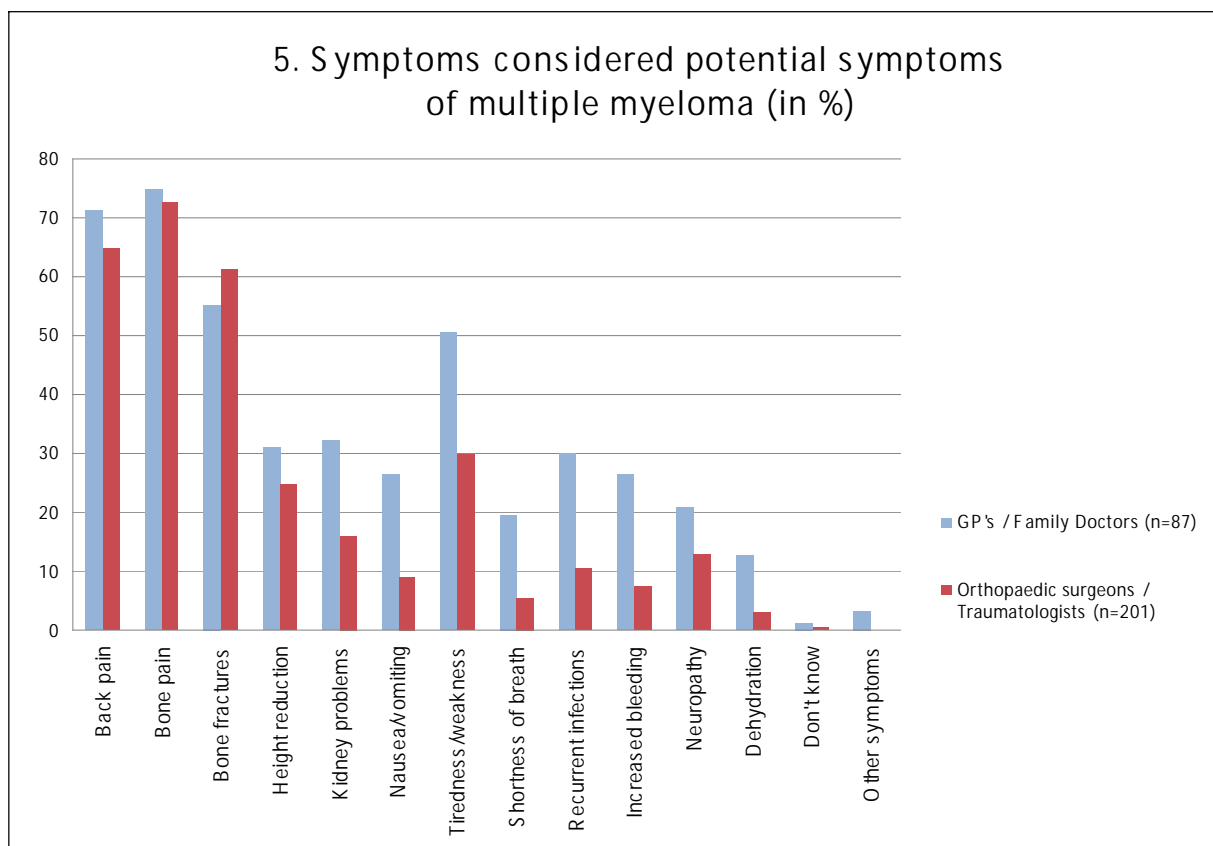
Question 5 for physicians:

“Which of the following would you consider a potential symptom of multiple myeloma? Please tick all that apply.”

(1) = Back pain; 2) = Bone pain; 3) = Bone fractures; 4) = Height reduction; 5) = Kidney problems; 6) = Nausea/vomiting; 7) = Tiredness/weakness; 8) = Shortness of breath; 9) = Recurrent infections (Bacterial pneumonia, urinary tract infections, and shingles); 10) Increased bleeding; 11) = Neuropathy; 12) = Dehydration; 13) = Don't know; 14) = Other

It was possible to tick more than one answer option.

For the general practitioners/family doctors and orthopaedic surgeons and traumatologists who answered this question, the symptom that they associated with multiple myeloma the most was bone pain (74.7% / 72.6%), followed by back pain (71.3% / 64.7%), bone fractures (55.2% / 61.2%) and tiredness/ weakness (50.6% / 29.9%). Generally speaking, general practitioners/family doctors associate more symptoms with multiple myeloma than orthopaedic surgeons and traumatologists do.



Graph 10) Symptoms considered potential symptoms of multiple myeloma (in %)

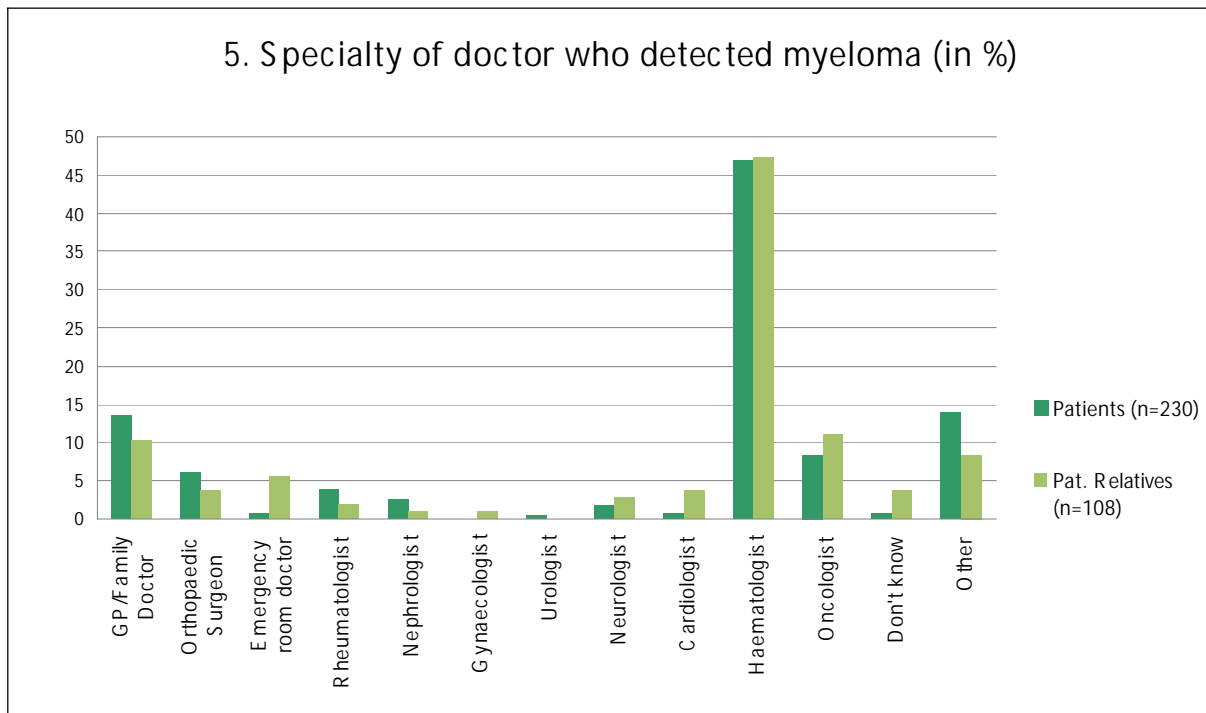
Question 5 for myeloma patients/patient relatives:

“Please indicate the specialty of the doctor who detected your (your family member's) myeloma:”

(1) = General Practitioner/Family Doctor; 2) = Orthopaedic Surgeon; 3) = Emergency room doctor; 4) = Rheumatologist; 5) = Nephrologist; 6) = Gynaecologist; 7) = Urologist; 8) = Neurologist; 9) = Cardiologist; 10) = Haematologist; 11) Oncologist; 12) = Don't know; 13) Other

When asked about the specialty of the doctor who detected their myeloma, about half of the myeloma patients (47%) and of the patients represented by their relatives (47.2%) who have answered this question said that their myeloma was detected by a haematologist. In about one in ten cases, it was a general practitioner/family doctor (13.5% / 10.2%) or an oncologist (8.3% / 11.1%) who detected the myeloma, and only in about 1 in 20 cases was the myeloma detected by an orthopaedic surgeon (6.1% / 3.7%).

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



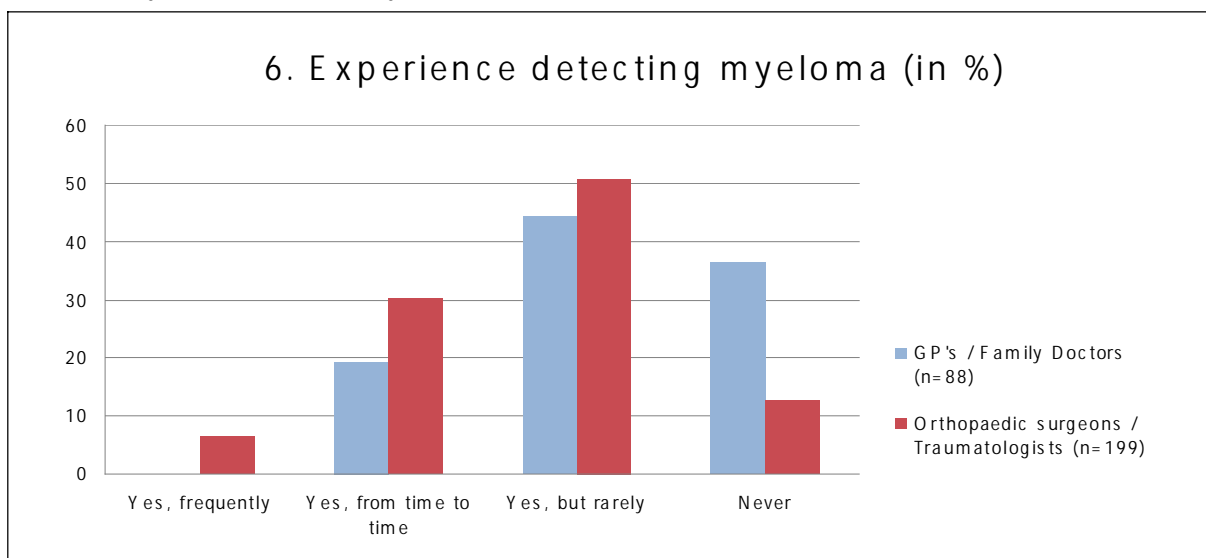
Graph 11) Specialty of doctor who detected myeloma (in %)

Question 6 for physicians:

“Have you already detected myeloma in one or more of your patients?”

(1) = Yes, frequently; 2) = Yes, from time to time; 3) = Yes, but rarely; 4) = Never

The majority of general practitioners/family doctors and orthopaedic surgeons and traumatologists who responded to this question stated that they have “rarely” or “never” detected multiple myeloma in one of their patients (80.7% / 63.31%). However, about one in five general practitioners/family doctors (19.3%) and one in three orthopaedic surgeons and traumatologists (30.2%) stated that they have detected myeloma “from time to time.”



Graph 12) Experience detecting myeloma (in %)

Question 6 for myeloma patients/patient relatives:

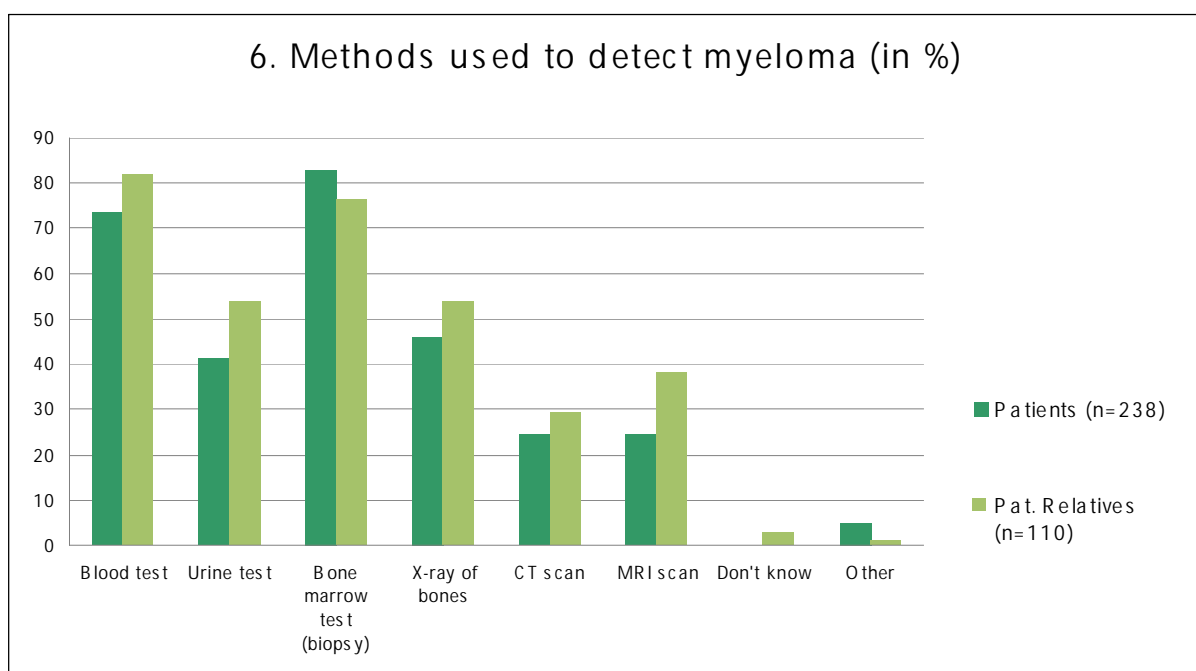
“Which of the following methods were used to detect your (your family member’s) myeloma?”

(1) = Blood test; 2) = Urine test; 3) = Bone marrow test (biopsy); 4) = X-ray of bones;
5) = Computerised Tomography (CT) scan; 6) = Magnetic Resonance Imaging (MRI) scan; 7) = Don’t know; 8) = Other)

It was possible to tick more than one answer option.

According to the myeloma patients and the patients represented by their relatives who have responded to this question, the most frequently used methods to detect myeloma are bone marrow biopsy (82.8% of patients and 76.4% of patient relatives) and blood testing (73.5% / 81.8%), followed by x-ray of bones (45.8% / 53.6%), urine testing (41.2% / 53.6%), MRI scan (24.4% / 38.2%) and CT scan (24.4% / 29.1%).

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



Graph 13) Methods used to detect myeloma (in %)

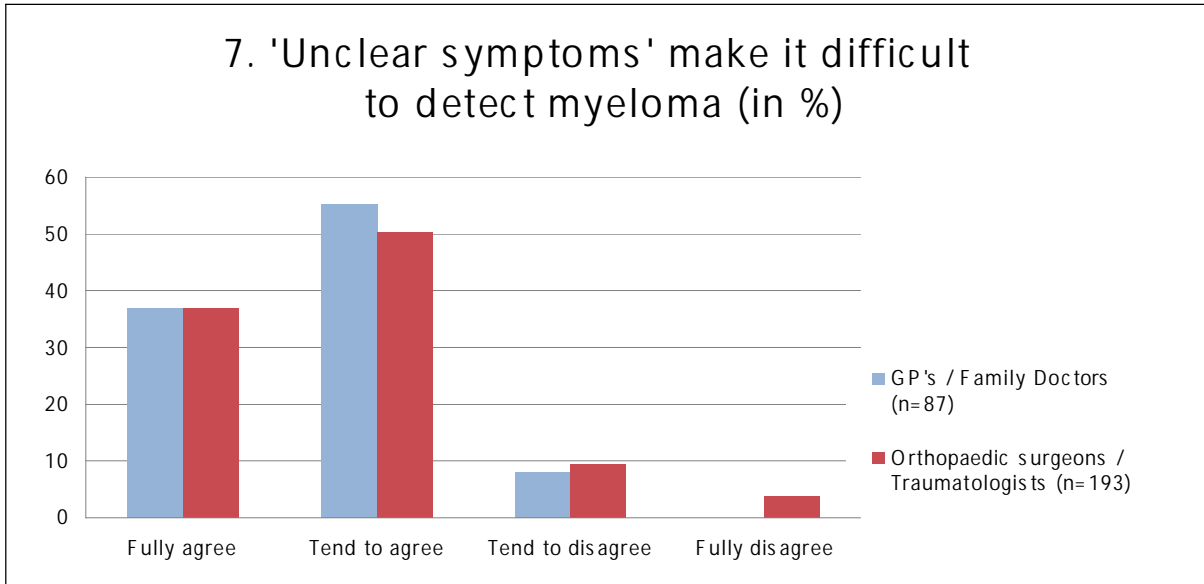
Question 7 for physicians:

“An earlier Myeloma Euronet survey has shown that ‘unclear symptoms’ constitute the greatest barrier to early myeloma diagnosis. Would you say that ‘unclear symptoms’ make it difficult to do appropriate tests?”

(1) = Fully agree; 2) = Tend to agree; 3) = Tend to disagree; 4) = Fully disagree)

The majority of general practitioners/family doctors and orthopaedic surgeons and traumatologists who answered this question agreed that ‘unclear symptoms’ make it difficult to do appropriate diagnostic tests in order to detect multiple myeloma. More than one-third of both groups “fully agreed” (36.8% each) and about half of the respondents “tended to agree” with this observation (55.2% / 50.3%) that was first revealed in an international comparative Myeloma Euronet survey conducted in 2006.

In that survey, 95 physicians (77% of whom were haematologists) and 42 myeloma patients and patient relatives, mainly from European countries, had stated that unclear or missing symptoms were the greatest barrier to myeloma diagnosis in their countries. The summary report of that survey is available for download in the surveys section of the Myeloma Euronet Web site at www.myeloma-euronet.org.



Graph 14) 'Unclear symptoms' make it difficult to detect myeloma (in %)

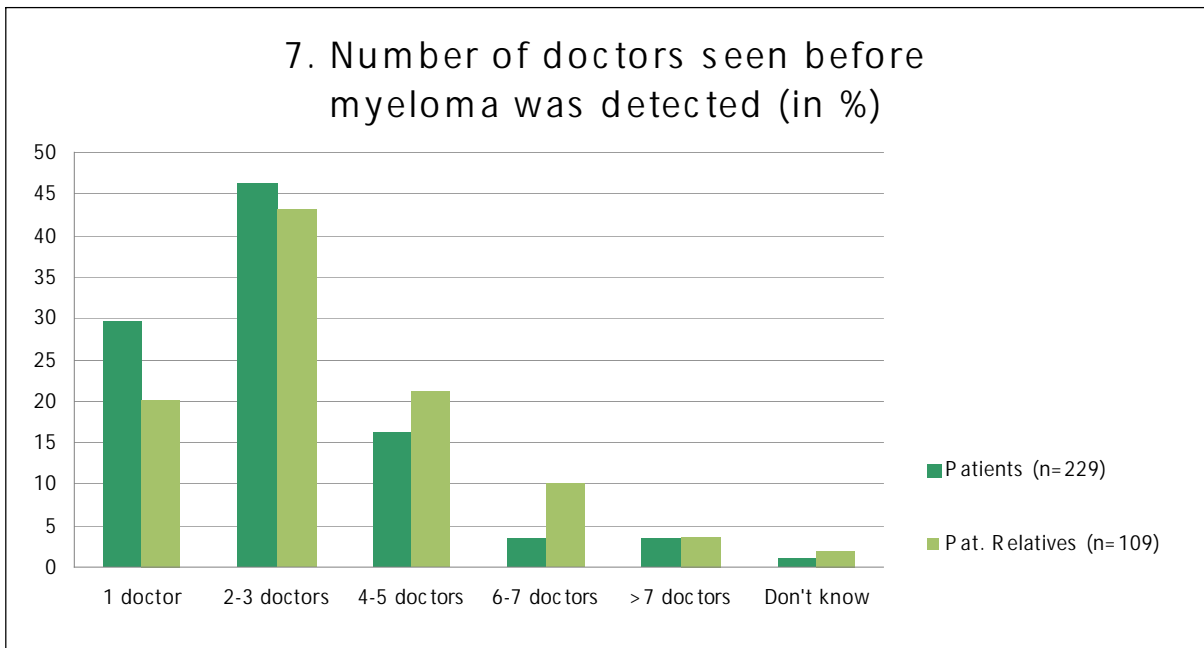
Question 7 for myeloma patients/patient relatives:

“Looking back, how many doctors did you (your family member) see before the myeloma was detected?”

(1) = Just 1 doctor; 2) = 2-3 doctors; 3) = 4-5 doctors; 4) = 6-7 doctors; 5) = More than 7 doctors; 6) = Don't know)

Of the myeloma patients who answered this question, about three-quarters (76%) stated that they had seen 1-3 doctors before their myeloma was detected but almost one in four patients (23.1%) had to see 4 doctors or more before the cause of their symptoms was identified. According to the myeloma patient relatives who responded to this question, only about two-thirds of patients (63.3%) had to see 1-3 doctors before their myeloma was detected and more than one-third (34.9%) stated that it took 4 doctors or more to identify the cause of the symptoms.

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



Graph 15) Number of doctors seen before myeloma was detected (in %)

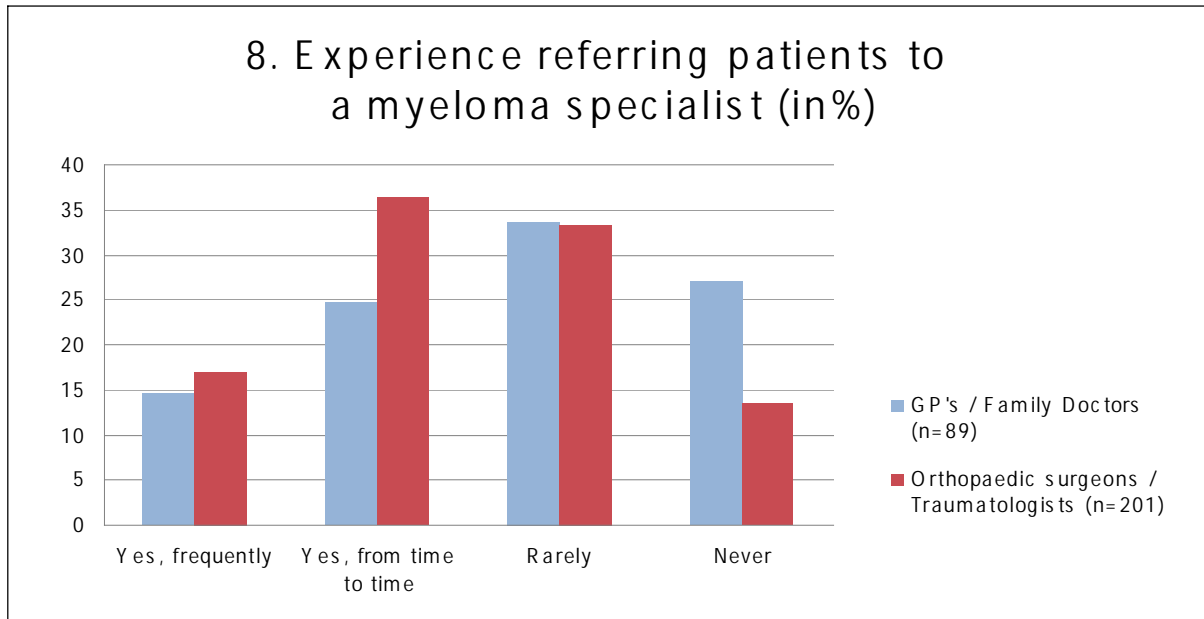
Question 8 for physicians:

“Have you already referred one or more of your patients to a multiple myeloma specialist?”

(1) = Yes, frequently; 2) = From time to time; 3) = Rarely; 4) = Never)

Almost two-thirds of the general practitioners/family doctors (60.7%) and about half of the orthopaedic surgeons and traumatologists (46.8%) who responded to this question stated that they have “rarely” or “never” referred one or more of their patients to a multiple myeloma specialist.

However, more than one in three general practitioners/family doctors (39.3%) and more than one in two orthopaedic surgeons and traumatologists (53.2%) responded that they have “frequently” or “from time to time” referred one or more of their patients to a myeloma specialist. This again confirms that orthopaedic surgeons and traumatologists tend to be more familiar with multiple myeloma than general practitioners/family doctors.



Graph 16) Experience referring patients to a myeloma specialist (in %)

Question 8 for myeloma patients/patient relatives:

“How much time passed from initial consultation (see question 1) until the myeloma was detected?”

(1) = ≤1 week; 2) = 1-2 weeks; 3) = 3-4 weeks; 4) = 1-2 months; 5) = 3-4 months; 6) = 5-6 months; 7) = 7-12 months; 8) = 13-18 months; 9) = 19-24 months; 10) = >2 years; 11) Don't know)

According to the answers given by myeloma patients and patient relatives, it took less than 1 week until the myeloma was detected in about one in ten cases (9.1% / 8.3%), following the initial consultation. In about one in three cases (according to myeloma patients, 31.6%) and in about one in eight cases (according to patient relatives, 13%), it took 1-4 weeks to detect the myeloma.

According to more than one in four myeloma patients and patient relatives (28.6% / 27.8%), it took 1-4 months before the myeloma was detected, and in about one in eight cases (according to myeloma patients, 13%) and more than one in four cases (according to patient relatives, 27.8%), the myeloma was not detected until 5-12 months after the initial consultation.

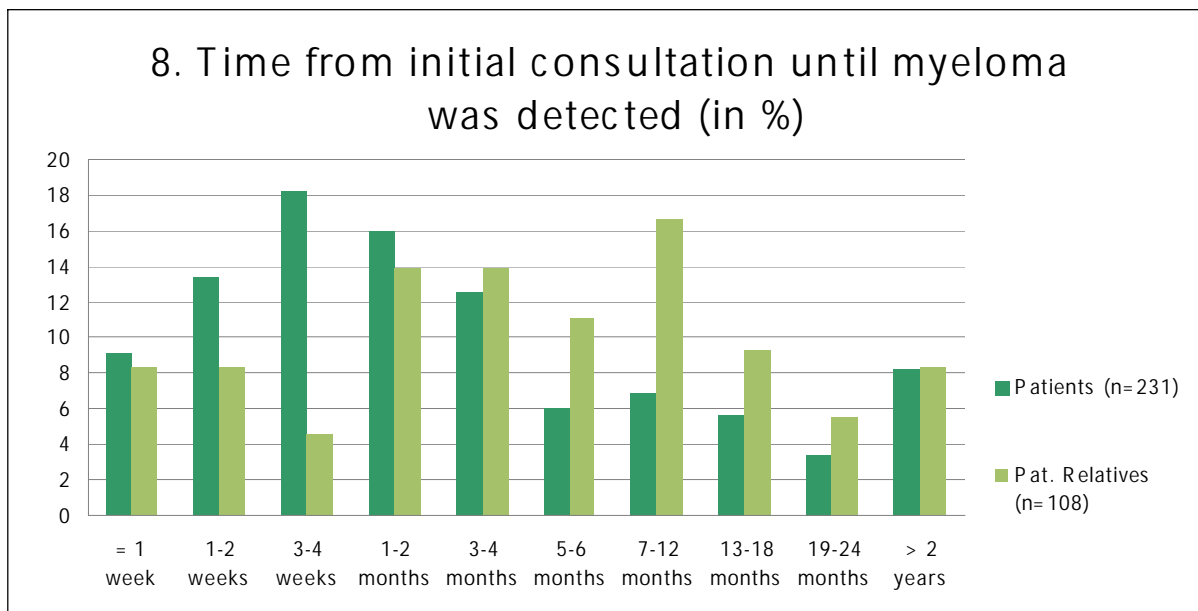
In about one in ten cases (according to myeloma patients, 9.1%) and in about one in seven cases (according to patient relatives, 14.8%), detecting the myeloma took 13 to 24 months, and in about one in twelve cases (8.2% / 8.3%) it took even more than 2 years until the myeloma was finally detected.

In total, according to myeloma patients, the myeloma was detected within 4 months in about two-thirds of patients (69.3%). However, according to patient relatives, the duration of 4 months for detecting myeloma applied to only about half of the myeloma patients (49.1%).

According to the myeloma patients who responded to this question, the average time that passed from initial consultation until the myeloma was finally detected was more than 164 days or about 5.5 months.

According to the patient relatives who answered this question, the average time it took to detect the myeloma was more than 236 days or close to 8 months. When combining the answers given by myeloma patients and patient relatives, the average time for detecting multiple myeloma is more than 187 days or slightly more than 6 months.

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



Graph 17) Time from initial consultation until myeloma was detected (in %)

Question 9 for physicians:

“Multiple myeloma is a rare but treatable disease that affects about 80,000 people in Europe at any one time. Public disease awareness is low and not every medical professional is familiar with multiple myeloma. Sometimes myeloma patients go undiagnosed for years and, if their myeloma is not detected, disease-related symptoms may be treated in a way that makes matters worse. When you see a patient presenting with one or more of the symptoms listed above (see question 5), would you agree in principle to check for myeloma (do a blood test, for example) before considering treatment for one or more of those symptoms?”

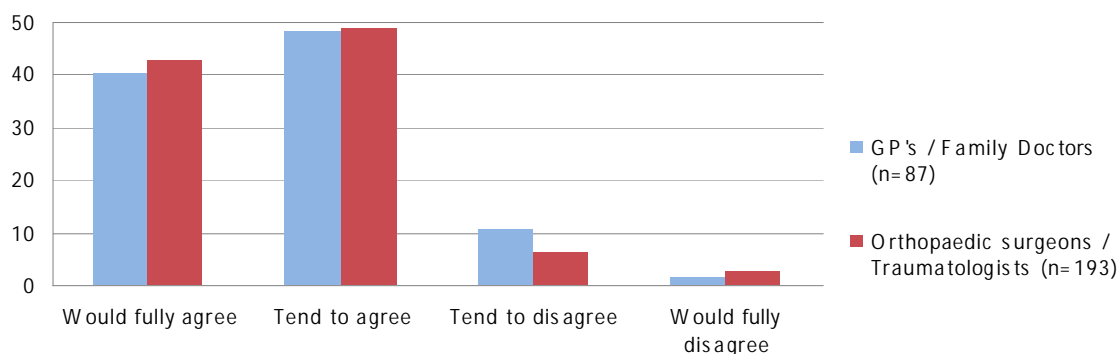
(1) = Would fully agree; 2) = Tend to agree; 3) = Tend to disagree; 4) = Would fully disagree)

5) = **IMPORTANT:** If you tend to or fully disagree, please explain why: ...

When asked about their readiness to check for myeloma (do a blood test, for example) when seeing a patient presenting with one or more of the aforementioned symptoms, the majority of the general practitioners/family doctors and the orthopaedic surgeons and traumatologists who answered this question (88.5% / 91.2%) stated that they “would fully agree” or “tend to agree” to check for myeloma before considering treatment.

Of the general practitioners/family doctors and orthopaedic surgeons and traumatologists who “tended to disagree” or “fully disagreed” with this approach (11.5% / 8.8%), only very few explained why they did not agree. Their reasons included statements such as: “Only in certain age group and if pain does not go away”; “These complaints are too frequent”; “Because all of them are very common symptoms”; “First try to treat, if no answer, [then we] should think [of] the other disease”; “Because it is not so frequent”; “These are symptoms which go together with so many other diseases.”

9. Readiness to check for myeloma before considering treatment (in %)



Graph 18) Readiness to check for myeloma before considering treatment (in %)

Question 9 for myeloma patients/patient relatives:

"In your opinion, what should be done to avoid delays in myeloma diagnosis?
Please tick all that apply."

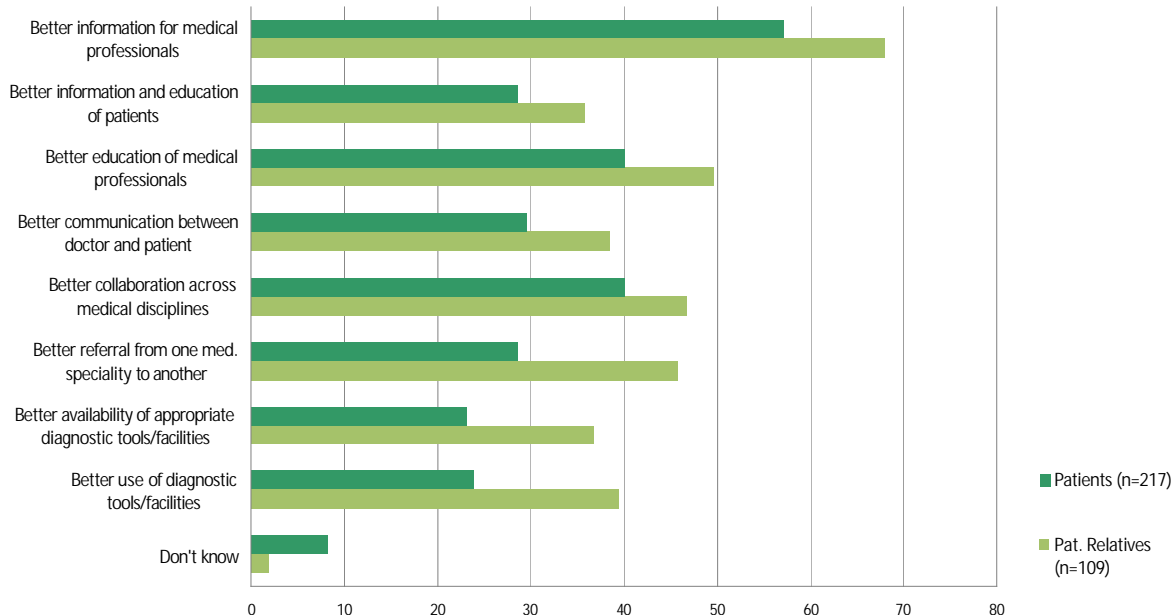
- (1) = Better information for medical professionals; 2) = Better information and education of patients;
3) = Better education of medical professionals; 4) = Better communication between doctor and patient;
5) = Better collaboration across medical disciplines; 6) = Better referral from one med. specialty to another;
7) = Better availability of appropriate diagnostic tools/facilities; 8) = Better use of diagnostic tools/facilities;
9) = Don't know; 10) = Other)

It was possible to tick more than one answer option.

The myeloma patients and patient relatives who answered this question agreed that the most important step to be taken in order to avoid delays in myeloma diagnosis is to provide better information for medical professionals (57.1% / 67.9%), followed by better education of medical professionals (40.1% / 49.5%) and better collaboration across medical disciplines (40.1% / 46.8%).

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

9. Steps to be taken to avoid delays in myeloma diagnosis (in %)



Graph 19) Steps to be taken to avoid delays in myeloma diagnosis (patients and patient relatives, in %)

Question 10 for physicians:

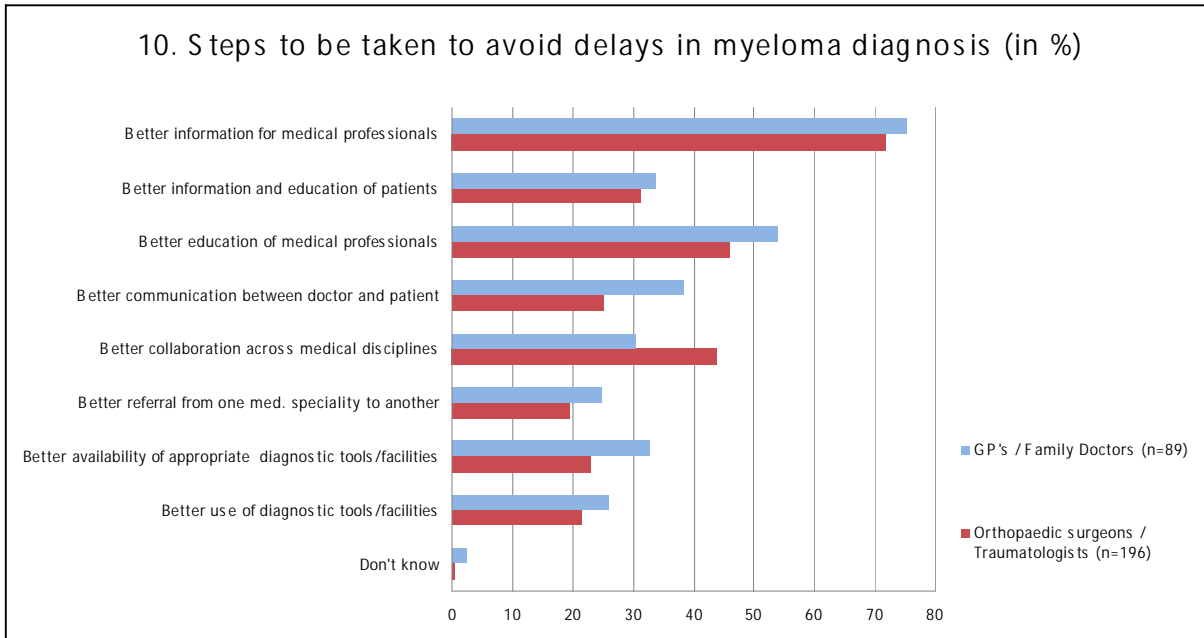
“As stated in question 9, myeloma patients sometimes go undiagnosed for years because their myeloma is not detected. In your opinion, what should be done to avoid delays in myeloma diagnosis?”

- (1) = Better information for medical professionals; 2) = Better information and education of patients;
- 3) = Better education of medical professionals; 4) = Better communication between doctor and patient;
- 5) = Better collaboration across medical disciplines; 6) = Better referral from one med. speciality to another;
- 7) = Better availability of appropriate diagnostic tools/facilities; 8) = Better use of diagnostic tools/facilities;
- 9) = Don't know; 10) = Other)

It was possible to tick more than one answer option.

The majority of the general practitioners/family doctors and the orthopaedic surgeons and traumatologists who responded to this question agreed that better information for medical professionals is the most important step that should be taken in order to avoid delays in multiple myeloma diagnosis (75.3% / 71.9%), followed by better education of medical professionals (53.9% / 45.9%).

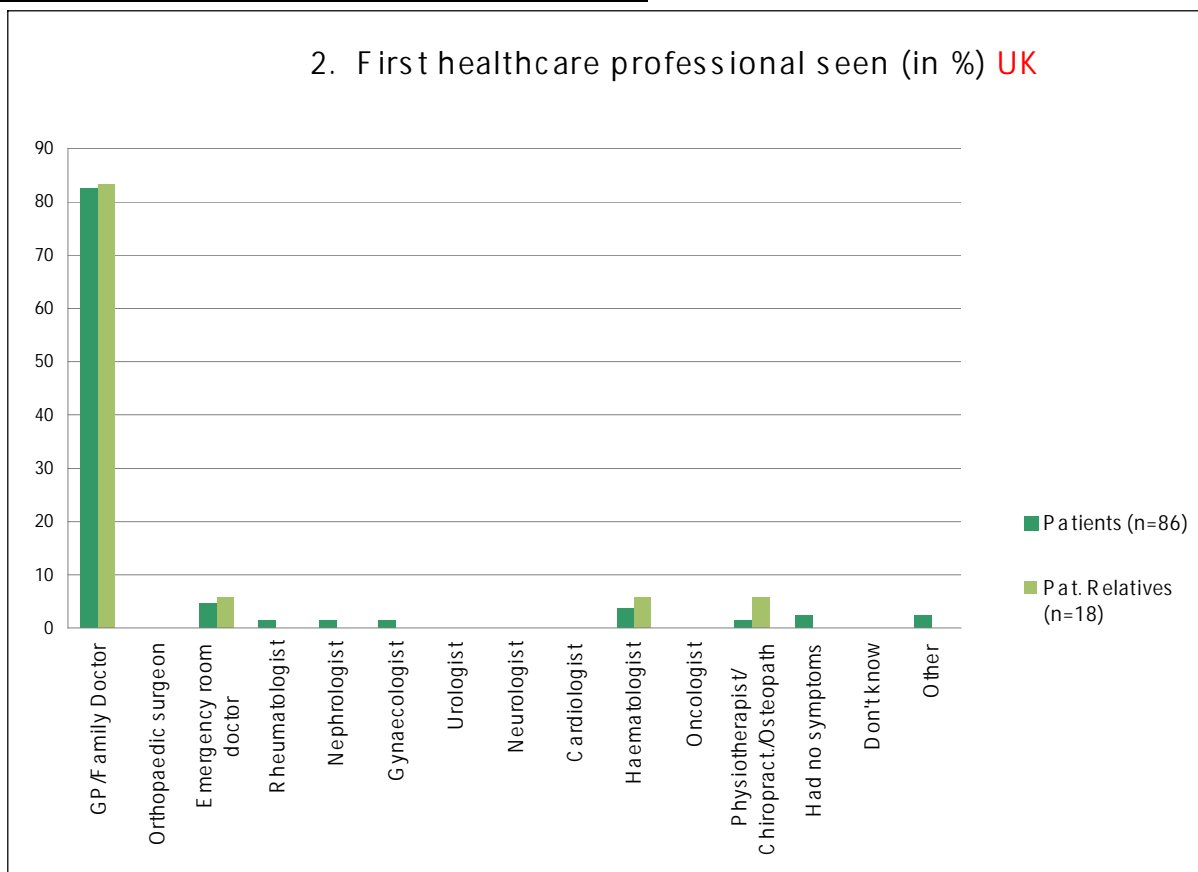
According to general practitioners/family doctors who participated in the survey, the third-most important step to avoid delays in myeloma diagnosis is to improve doctor-patient communication (38.2%), whereas orthopaedic surgeons and traumatologists felt that better collaboration across medical disciplines was the next important step to help speed up myeloma diagnosis (43.9%).



Graph 20) Steps to be taken to avoid delays in myeloma diagnosis (physicians, in %)

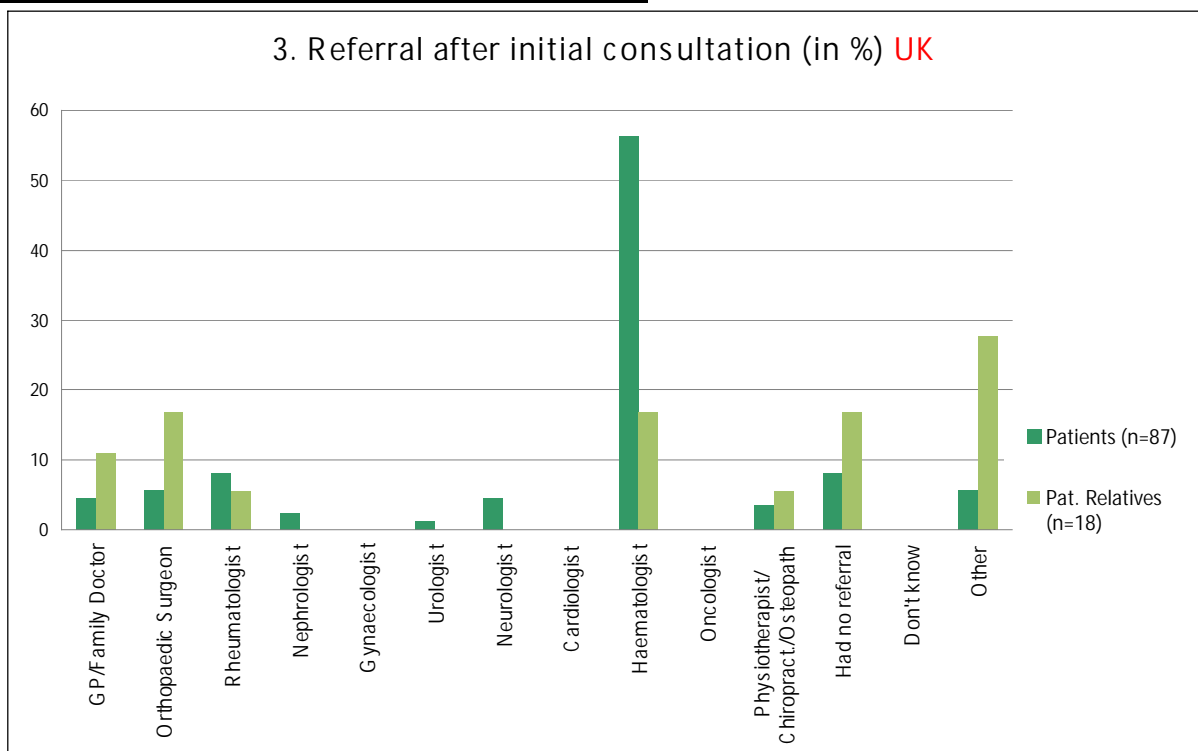
Additional Graphs

Question 2 for myeloma patients/patient relatives



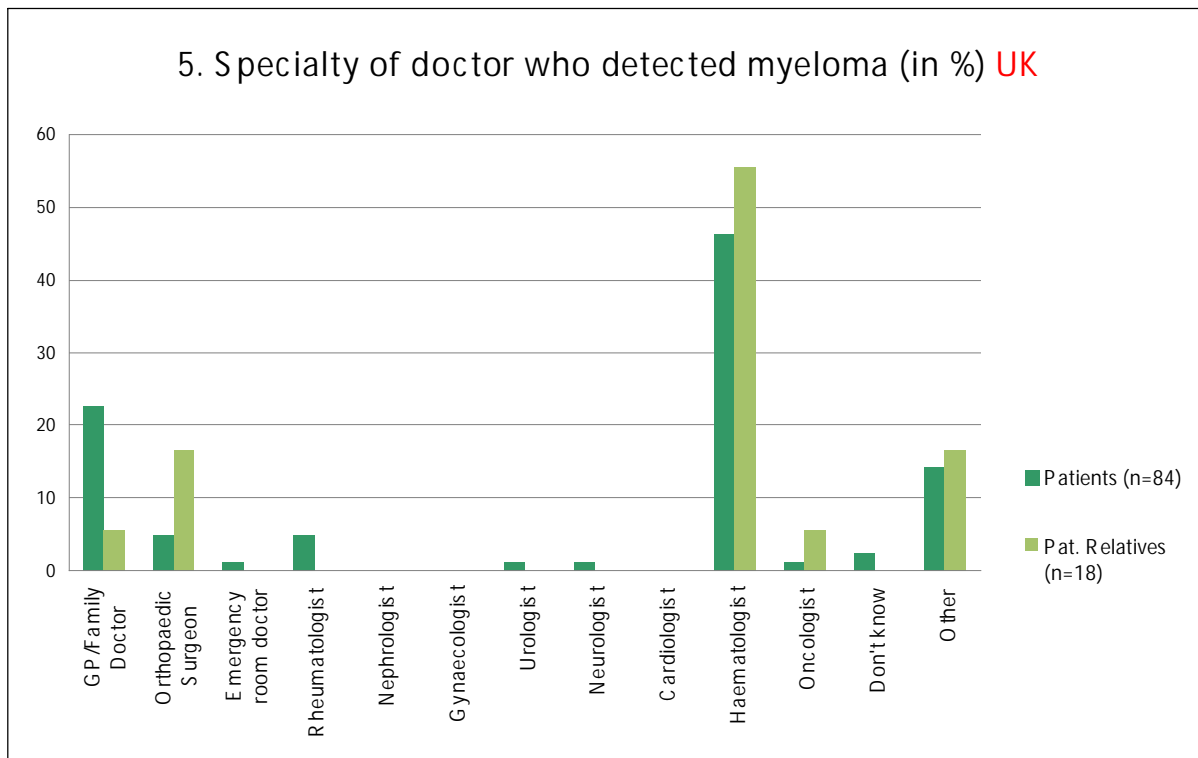
Graph 4a) First healthcare professional seen, as indicated by UK patients and patient relatives (in %)

Question 3 for myeloma patients/patient relatives



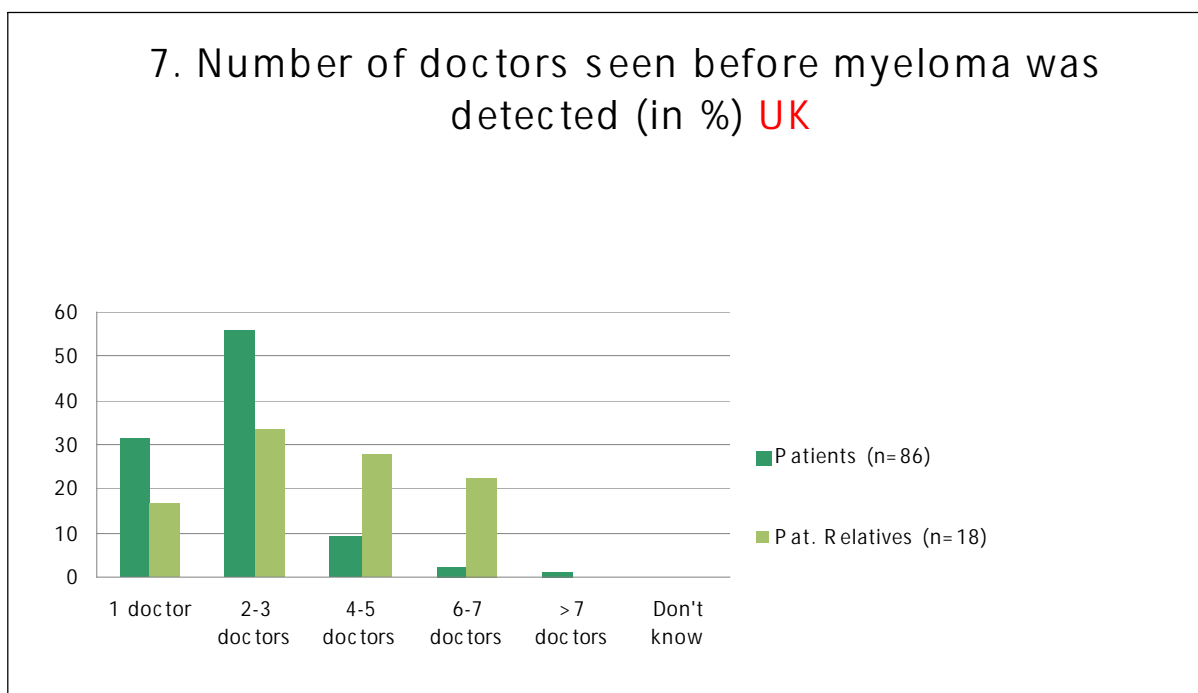
Graph 6a) Referral after initial consultation, as indicated by UK patients and patient relatives (in %)

Question 5 for myeloma patients/patient relatives



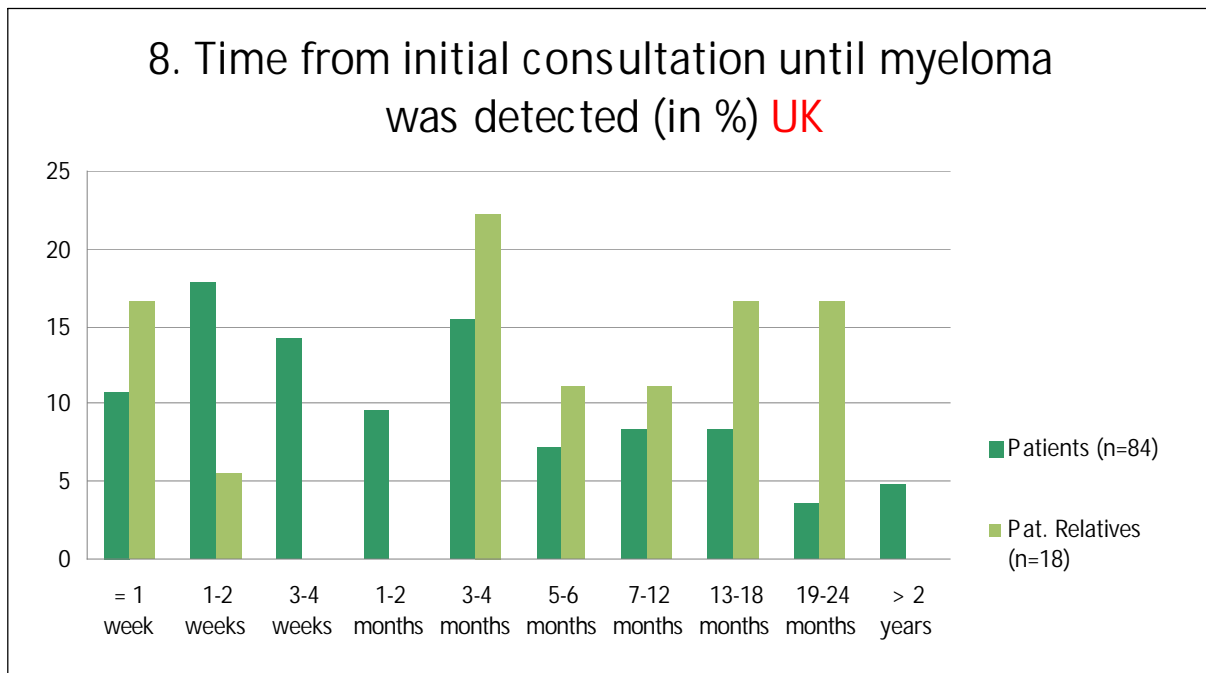
Graph 11a) Specialty of doctor who detected myeloma, as indicated by UK patients and patient relatives (in %)

Question 7 for myeloma patients/patient relatives



Graph 15a) Number of doctors seen before myeloma was detected, as indicated by UK patients and patient relatives (in %)

Question 8 for myeloma patients/patient relatives



Graph 17a) Time from initial consultation until myeloma was detected, as indicated by UK patients and patient relatives (in %)