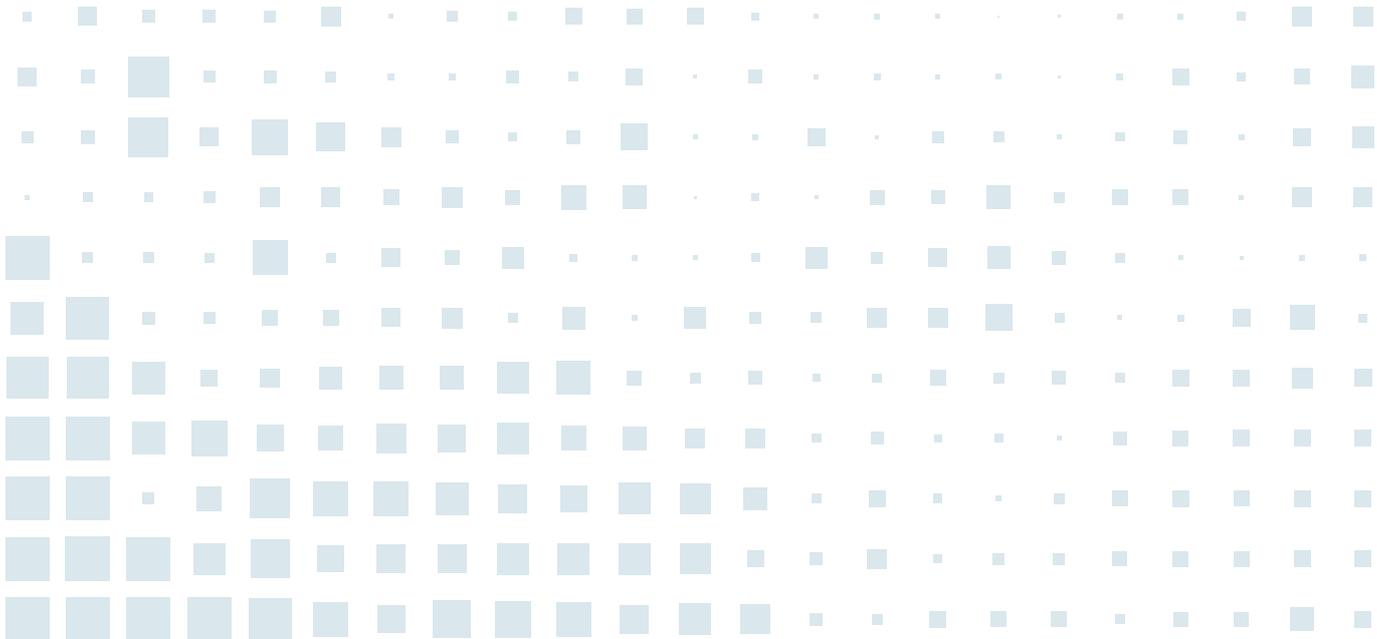




MYELOMA DIAGNOSIS ACROSS EUROPE

THE DIAGNOSIS EXPERIENCES OF
EUROPEAN MYELOMA PATIENTS AND
PERSPECTIVES FROM EUROPEAN
HAEMATOLOGISTS



EDITION

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EXECUTIVE SUMMARY

BACKGROUND

Early diagnosis of myeloma has been shown to minimise disease complications and improve quality of life. Yet, existing literature on myeloma and testimonials from patients highlight that many patients experience delays, often due to non-specific symptoms, lack of myeloma awareness in primary care or other causes. To further explore these issues, MPE conducted a pan-European study to capture patient diagnostic experiences, the impact of a later diagnosis and solutions to improve diagnosis.

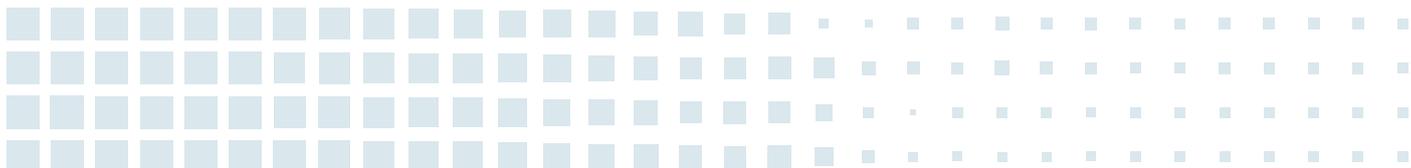
METHODS

A mixed-methods research methodology was chosen starting with a pan-European survey and followed by patient and haematologist focus groups and interviews. In total, 628 patients and 80 haematologists completed the survey. 23 patients and 6 haematologists took part in the focus groups and interviews.

KEY FINDINGS

Time to diagnosis:

- Approximately 51% of patients waited 3 or more months after the onset of symptoms before seeking medical help.
- 63% first presented with symptoms or received abnormal blood results at their GP and 11% at an emergency hospital department.
- Approximately 24% of patients waited 5 months or more to get a diagnosis.
- In contrast, 13% of haematologists stated it took their patients 5 months or more to get a diagnosis.



EXECUTIVE SUMMARY

Number of consultations:

- Most patients saw up to 3 different specialists (e.g. primary care, renal, orthopaedics) before receiving a diagnosis; however, 21% of patients saw more than 3.
- 14% of haematologists stated their patients saw more than 3 specialists.
- 45% of patients had more than 3 medical consultations and 22% had more than 6.
- 38% of haematologists reported that their patients typically had 3 medical consultations and 31% stated they had 4 or more.

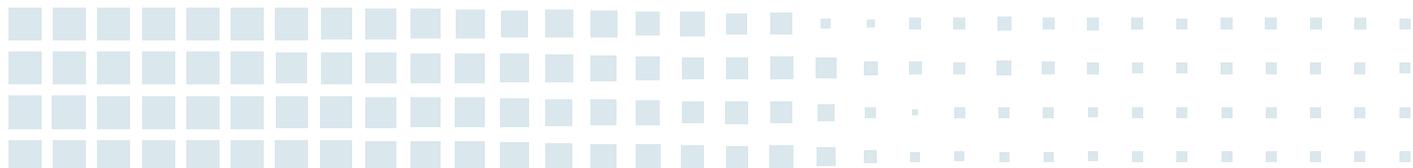
Delays in diagnosis

- Approximately 34% of patients stated that their diagnosis was delayed.
- 25% of clinicians described the timing of diagnosis in their country as delayed.

BARRIERS TO DIAGNOSIS AND IMPACTS

Patients and haematologists believed some of the largest barriers to timely diagnosis were the rarity and non-specific symptoms of myeloma, wrong department referrals, issues within healthcare systems, and lack of GP appointments. Other barriers raised related to COVID-19, geographical inequalities, and access to diagnostic tests.

Patients and haematologists also agreed that the impact of a delayed diagnosis can have significant long-term complications, which may affect treatment options and survival. They also agreed on a delayed diagnosis impacting quality of life and emotional wellbeing, family members, careers and finances and the undertaking of normal daily activities.



EXECUTIVE SUMMARY

RECOMMENDATIONS:

Based on the survey results and focus group discussions, MPE developed several recommendations to help improve diagnosis, which are summarised below:

- Awareness initiatives and decision-making aides for primary care to ensure doctors suspect myeloma and conduct the relevant tests and investigations, as appropriate.
- European and national referral guidelines for myeloma should be developed (where they don't already exist) and disseminated.
- Exploration and development of predictive risk algorithms to help estimate the risk of a patient having myeloma.
- Development of an online learning programme for GPs on myeloma and related conditions like AL amyloidosis, with continuous professional development points.
- Government funded public health campaigns which promote GP attendance if health changes and general symptom awareness of the signs of cancer.
- Expansion of a diagnosis pathway campaign to other healthcare specialists.
- Hospital specific, cross-speciality training to remind clinicians about the signs, symptoms and complications of different diseases.
- Haematologists to consider providing feedback during “teachable moments” where patients have experienced significant diagnosis delays that could have been avoided.
- Explore targeted screening approaches so patients are identified before becoming seriously unwell.
- Exploratory studies on the viability of screening tests or how the community better monitors MGUS and identifies high-risk patients before it progresses to myeloma.
- Monitor variations in diagnosis times and access to tests by national registries and health systems, and through initiatives in Europe's Beating Cancer Plan.
- Integration of comprehensive strategies to improve the diagnosis of myeloma, and other rare and difficult to diagnose cancers, in European and national cancer plans.

EXECUTIVE SUMMARY	3
INTRODUCTION	7
METHODS	9
Survey demographics	10
Focus groups and interview demographics	11
DIAGNOSIS PATHWAY	13
Barriers to seeking medical help	13
Patient definitions and experience of delayed diagnosis	16
BARRIERS TO TIMELY DIAGNOSIS	27
Theme one: Rarity of myeloma and non-specificity of symptoms	28
Theme two: Referral to wrong departments	30
Theme three: Health systems source and structure	30
Theme four: Short and unavailable GP appointments	31
Theme five: COVID-19	32
Theme six: Geographical inequalities	32
Theme seven: Access to tests and investigations	33
IMPACT OF A DELAYED DIAGNOSIS	35
Theme one: Long-term symptoms and complications	36
Theme two: Difficulties undertaking normal daily activities	37
Theme three: Impact on quality of life and emotional well-being	38
Theme four: Impact on family members and carers	39
Theme five: Impact on career and finances	40
Theme six: Treatment options and survival	41
DIAGNOSTIC SOLUTIONS	42
Theme one: GP awareness and diagnosis aids	43
Theme two: Continuous professional development	44
Theme three: General population awareness of looking after their own health	45
Theme four: Raising awareness amongst “other” specialists	46
Theme five: Communication between primary and secondary care	47
Theme six: Potential of screening	48
Theme seven: Policy initiatives	50
LIMITATIONS	51
CONCLUSIONS	52
ACKNOWLEDGEMENTS	53
APPENDICES	54
REFERENCES	55



INTRODUCTION

MYELOMA PATIENTS EUROPE (MPE) IS AN UMBRELLA ORGANISATION OF 48 MYELOMA AND AL AMYLOIDOSIS PATIENT GROUPS AND ASSOCIATIONS FROM 31 COUNTRIES ACROSS EUROPE.

MPE has completed a Year of Action on Diagnosis to raise awareness, gather real-world insights, and implement a range of initiatives to promote the timely diagnosis of myeloma and AL amyloidosis in Europe. The publication of this report marks the culmination of this work and presents data and testimonials generated throughout the course of the Year.

THE CHALLENGE WITH MYELOMA DIAGNOSIS

Myeloma is a rare cancer of the plasma cells found in the bone marrow. Approximately 50,000 people in Europe are diagnosed each year with myeloma. ⁽¹⁾ Early diagnosis of myeloma is very important for these patients and their quality of life. Those who experience long delays in diagnosis are more likely to have an increased number of myeloma complications, be diagnosed with later stage disease and have reduced disease-free survival. ⁽²⁾

Despite the importance of early diagnosis, many patients experience delays. The rarity of myeloma, the non-specificity of symptoms (such as back pain and fatigue) and the average age of patients being over 65, collectively mean it is a very difficult cancer to diagnose for general practitioners (GPs) (i.e. primary care doctors). ⁽³⁾ MPE routinely hears from myeloma patients that have been misdiagnosed with more common conditions, before finally being referred to a haematology department and having a diagnosis confirmed. Patients also commonly report presenting at their GP numerous times before referral and convoluted pathways to diagnosis such as being referred to a non-haematology secondary care department (such as renal or orthopaedic clinics).

A literature review undertaken by MPE confirmed patient testimonials and found the following:

- Patients are often slow in seeking help from primary care. Evidence highlighted that myeloma patients experience symptoms for around 1 month before seeking help from primary care and 25% of patients wait more than 3 months. ⁽⁴⁾
- The median time to diagnosis in myeloma is 108.6 days, with 25% of patients waiting longer than 8 months for a diagnosis. ⁽⁵⁾
- Myeloma patients are more likely to present 3 or more times in primary care before being referred to secondary care. ⁽⁶⁾
- It is common for myeloma patients to present through emergency hospital settings. A study done in the UK found that 34% of patients were diagnosed via emergency settings. ⁽⁷⁾ Some patients may present in emergency settings because of delays in the health system, however, it is likely to be associated with disease aggression and risk status. ⁽⁸⁾

INTRODUCTION

Unlike in more common cancers, particularly in solid tumours (such as breast, prostate and bowel cancers), there is no routinely available screening programme for myeloma. Whilst it is known that all myeloma patients have a non-cancerous precursor condition called monoclonal gammopathy of undetermined significance (MGUS), it is not yet fully understood how to predict which patients will go on to develop myeloma. Widespread screening for MGUS could therefore potentially lead to an overdiagnosis of the condition in patients who otherwise remain healthy.⁽⁹⁾ In the future, being able to screen for MGUS and predict the patients who will develop myeloma is a key avenue to explore for improving the diagnosis of myeloma. In the interim, however, we need non-screening solutions to improve the diagnosis experience of myeloma patients.

RATIONALE FOR MPE STUDY AND REPORT

Given the outlined feedback from patients on their diagnosis experience, and the evidence uncovered in the literature review, MPE wanted to further explore these issues and understand directly from European myeloma patients and their doctors (haematologists) about their diagnosis experience. MPE was also interested to hear about the perceived impact of a delayed diagnosis and ideas on how the situation can be improved so it can develop and advocate for strategic solutions that improve outcomes for myeloma patients and their families across Europe.

To this end, MPE conducted a pan-European study on the diagnosis experience of myeloma patients. This included a quantitative survey with myeloma patients followed up with qualitative interviews with haematologists and focus groups with patients. The detailed findings and results from this study are presented in this MPE report, alongside advocacy recommendations for potential solutions and next steps for the myeloma community and other stakeholders including policy makers, healthcare professionals (including GPs and haematologists) and professional societies.

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”

METHODS

A MIXED-METHODS RESEARCH METHODOLOGY WAS CHOSEN TO GATHER PATIENT AND HAEMATOLOGIST PERSPECTIVES ON PATIENT EXPERIENCE OF DIAGNOSIS.

PATIENT AND HAEMATOLOGIST SURVEY

Between February 2022 and June 2022, MPE ran a survey to collect the diagnostic experiences of myeloma patients across Europe. Simultaneously, a survey to collect the perspectives on diagnosis and impact from a clinician's viewpoint was also released. Get Feedback was chosen as the survey platform based on feedback from patients on the clear display and usable navigation. Both surveys were translated into 27 European languages.

Survey questions were designed by MPE and informed by a non-systematic literature review. Questions aligned around the following themes:

- Barriers to seeking medical help
- Diagnosis timing
- Impact of a late diagnosis
- Solutions to improve diagnosis

Survey questions were reviewed by the MPE Taskforce, a group of patients and patient advocates able and trained to review and provide feedback on patient-focused research design. They were also reviewed by the MPE Medical Advisory Committee, a group of key opinion leaders in myeloma representing different countries across Europe. Once translated, MPE members checked the quality and clarity of the translation prior to dissemination.

The final questions included in the patient and haematology surveys can be found in the Appendices of this report (see Appendix 1).

INTERVIEWS AND FOCUS GROUPS

In depth patient focus groups and interviews were held with myeloma patients and haematologists to further explore the results highlighted in the survey. They were facilitated by at least one member of MPE staff. More specifically:

- **5 patient focus groups** were held to better understand the survey results and gain deeper insights into issues related to timely diagnosis.
- **3 patient interviews** were held with those unable to attend the scheduled focus groups
- **6 interviews** were held with haematologists

METHODS

Originally it was planned to conduct focus groups with haematologists; however, interviews were selected due to scheduling challenges. The detailed demographics for the interviews and focus groups are outlined below.

Focus group and interview scripts were developed by MPE, using open-ended questions and informed using the results of the literature review and survey (see Appendix 2 and Appendix 3). Participants were also sent the results of the patient and haematologist survey as a pre-read (see Appendix 4). Questions aligned to the same core themes as the survey questions.

SURVEY DEMOGRAPHICS

PATIENT SURVEY

In total, 628 myeloma patients completed the survey, across 28 European countries (see Appendix 5). 330 patients were female and 298 were male. To be eligible to participate in the survey, patients were required to have a diagnosis of active myeloma. Whilst smouldering myeloma patients were not included in the survey, 87 patients had a previous diagnosis of smouldering myeloma before being diagnosed with active myeloma.

HAEMATOLOGIST SURVEY

80 haematologists across 16 European countries completed the survey (see Appendix 5). Participants mostly worked in a general haematology department, a specialist myeloma department or an academic centre or hospital.

Table 1: Healthcare professional survey participants' work environment

Work environment	Haematologists
General haematology department	45
Academic centre or hospital	27
Specialist myeloma department	25
Local hospital	10
Specialist AL amyloidosis department (e.g., in a national amyloidosis referral centre)	4
General oncology department	1
Patient organisation	1
Private oncology clinic	1

METHODS

FOCUS GROUPS AND INTERVIEW DEMOGRAPHICS

PATIENT FOCUS GROUPS

Four English-speaking focus groups and one Spanish-speaking focus group were held. Three English-speaking interviews and two Lithuanian-speaking interviews were also held with patients, each lasting up to two hours. Focus groups and interviews were transcribed, and thematic analysis was used to generate the findings in this report. The Spanish-speaking focus group and Lithuanian-speaking interviews were transcribed and then translated into English prior to analysis.

In total 23 patients, aged between 34 and 75 (mean= 58), participated from 12 countries (see Table 2). 18 patients were male and 5 were female.

HAEMATOLOGIST INTERVIEWS

6 individual interviews were also conducted with haematologists across 5 different countries (see Table 2). All participants worked in haematology or general oncology departments, of which four participants worked in academic hospitals and two in local hospitals.

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In total 23 patients,
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”

METHODS

Table 2: Country specific patient and clinician demographics

Country	Patients		Haematologists	
	Survey	Focus groups and interviews	Survey	Interview
Armenia			1	
Austria	33			
Belgium	60	3	3	
Bosnia and Herzegovina	1			
Croatia	8			
Czech Republic			1	1
Denmark	68	2		
Finland	20	1		
France	6	2	1	2
Germany	15	3		
Greece	1			1
Ireland	15			
Israel	51	2	6	
Italy	6		11	
Latvia	1			
Lithuania	4	2		
North Macedonia	1			1
Netherlands	143	1	1	
Norway	22	1		
Other	16		5	
Poland	46	1	7	
Portugal	2			
Romania	13		17	
Russia	6		1	
Serbia	1		2	
Slovenia	1			
Spain	16	2	15	
Sweden	2		1	
Switzerland	45			
Turkey	2		1	
United Kingdom	23	3	7	1
Total	628	23	80	6

DIAGNOSIS PATHWAY

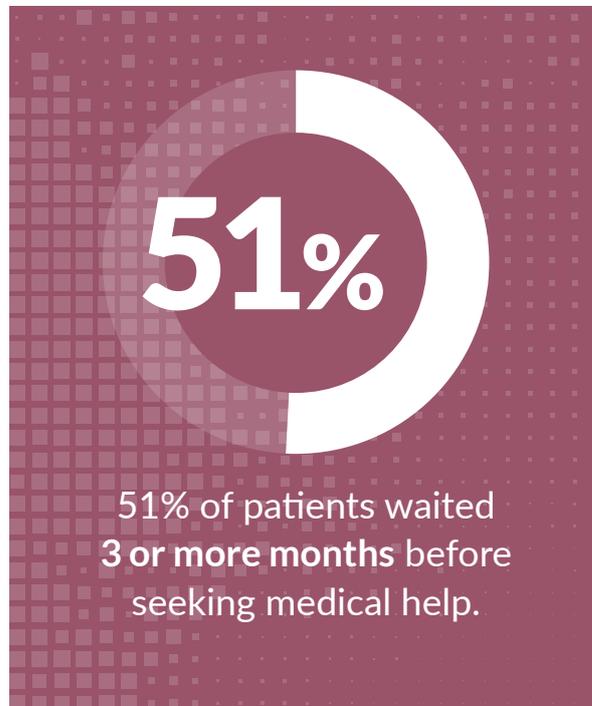
BARRIERS TO SEEKING MEDICAL HELP

The research found that myeloma patients often wait too long before presenting to the GP with symptoms, which adds a delay before the patient enters a healthcare system.

The most common reason for this was the non-specific presenting symptoms being confused for symptoms of more common conditions or general ageing. There are also systemic factors at play, such as lack of GP appointments, which prevent patients seeking or accessing medical help.

Evidence identified in the literature review outlined that myeloma patients may be slow in seeking help from GPs in primary care, with patients sometimes experiencing symptoms for over a month before seeking medical help. ⁽¹⁰⁾ However, it is important for patients to be diagnosed as soon as possible after symptoms begin.

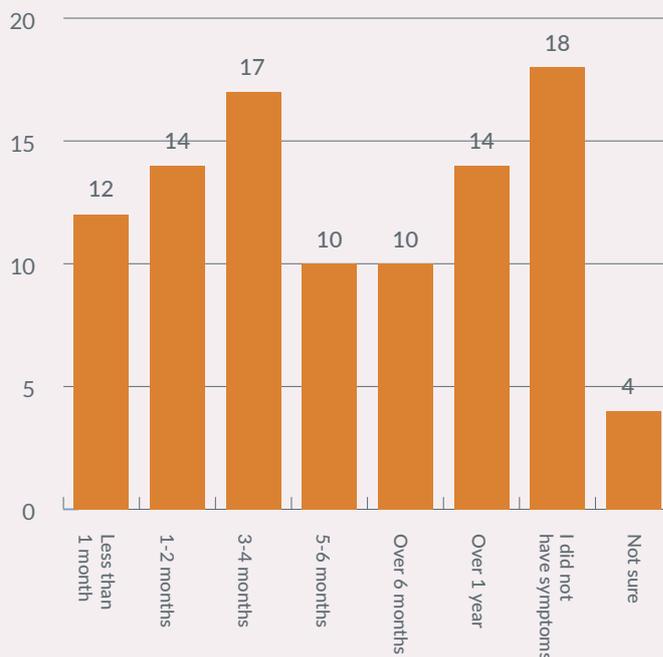
The results of the patient survey found that while many patients sought help within 2 months, 51% of patients waited 3 or more months before seeking medical help. 14% of respondents waited longer than



1 year. A corresponding question was not asked in the haematologist survey; however, their perspectives were sought in the interviews.

Patient responses

Percentage of responses for how many months patients experienced symptoms before seeking medical help.



DIAGNOSIS PATHWAY

Various reasons were raised in the focus groups and interviews as to why patients delay seeking medical help. The most common reason raised by patients was the non-specific symptoms associated with myeloma, such as, back pain and fatigue and fact they are correlated to symptoms of general ageing and routine activities. This prevented them from linking these symptoms to a more severe illness.



I was suffering from what we all thought at the time to be middle aged, lower back pain syndrome. That was getting worse and worse to the point where over Christmas time I was taking quite a lot of painkillers and it was very clear to me when they started wearing off... I got up to walk around and I sneezed and found myself lying on the floor with tingly legs. And that's when I decided to go and see a doctor.

– MYELOMA PATIENT, UNITED KINGDOM



Patients like myself think 'Yes, I have some pain in my lower back so why should I go to the doctor? I have to be careful with my movements and I take some rest.

– MYELOMA PATIENT, THE NETHERLANDS



This also happens when people have less severe symptoms – they wait for whatever reason before they go to their GP. Unless there is a heavy injury to your body, you don't go.

– MALE PATIENT, BELGIUM

Secondly, as well as disease specific reasons for delaying initial presentation, there may also be health system related factors and administrative burdens that prevent a patient from seeking medical help or delay patients getting their initial appointment with a GP.

A number of focus groups highlighted disparities and burden of trying to access GP appointments as a factor. This was particularly the case in countries where there are mixed systems of public (or statutory) and private healthcare insurance, such as Germany. Patients reported disadvantages to accessing timely appointments through the public healthcare system compared to private healthcare. Therefore, patients experiencing non-specific symptoms tend to delay booking GP appointments.



I didn't go to a public hospital... here in Finland, if you go to a public hospital, it might be half a year before you can see a specialist.

– MYELOMA PATIENT, FINLAND



Some people, they just don't want to go to the public side because they know that it will take time before they get a right kind of specialist. And then those who don't have any insurance, they don't want to go to private side because it costs too much.

– MYELOMA PATIENT, ISRAEL

Other health system related factors included GP shortages which cause long waiting times for patients. Whilst patients might attempt to seek medical help, the initial delay in presenting may be related to the length of time it takes to get an appointment.

GP retention was raised as a particular issue in more rural areas, exacerbating geographical inequalities in access to appointments and timely diagnosis. In relation to this, patients may also be less inclined to travel to GP appointments if they live further away from their GP and wait longer before seeking medical help.

DIAGNOSIS PATHWAY



We are facing a huge medical crisis currently in terms of number of physicians, number of GP's and number of doctors that are working in hospital and in the public environment.” – Myeloma patient, France “We are facing a huge medical crisis currently in terms of number of physicians, number of GP's and number of doctors that are working in hospital and in the public environment.

– MYELOMA PATIENT, FRANCE



If it's particularly difficult for a patient to get an appointment with their GP then they may not try until their symptoms are really bad.

– HAEMATOLOGIST, UNITED KINGDOM



There's a barrier to being able to go to the GP in the first place. If there's a lack of GP appointments, for example, or a delay or it takes three months to get your first appointment.

– HAEMATOLOGIST, NORTH MACEDONIA

Participants in the focus groups and interviews were also asked about individual and socioeconomic barriers in seeking medical help. For example, factors such as sex, educational background and race. Some patients and clinicians did not think socio-economic factors played a big role in patients delaying medical help, however gender, culture, language proficiency and education were discussed by others as potential factors in delays. It is important to highlight the limitations of the diversity of participants involved in this research, therefore this report may not accurately capture some ethnicity, community or country-specific socioeconomic issues patients may face during their diagnosis experience. Future research should explore this further.



I met a couple of guys in the network that I visited, they are completely alone with their illness. They don't talk to their wives. They don't talk to their kids and the truth is not because they do not want to talk about it. It's just that they have a standing in the family and a position in a family where they don't know how to talk to their GP about it.

– MYELOMA PATIENT, DENMARK



Patients do not ask questions because they fear that they are seen as not intelligent and therefore they do not ask for that.

– MYELOMA PATIENT, GERMANY



People with less income have less possibilities to get medical help, because if they need to travel to a certain place or do some specific tests, they do not have money for that....in our society it is common that people do not really take care of themselves until something bad happens.

– MYELOMA PATIENT, LITHUANIA



Ethnicity or gender factors? No, not in France, but social or professional factors, yes. Professional, absolutely, because... one of the problems facing the diagnosis of myeloma is that when you have back pain, and when you have been someone working in agriculture... or in building construction etc., you will naturally suffer from back pain, because it has to do with your work.

– HAEMATOLOGIST, FRANCE



I would say that definitely the economic status and the social status of the patient plays an important role in asking for help.

– HAEMATOLOGIST, GREECE

DIAGNOSIS PATHWAY

PATIENT DEFINITIONS AND EXPERIENCE OF DELAYED DIAGNOSIS

The research found that patients and haematologists agreed a delayed diagnosis relates to symptoms and complications patients are experiencing at diagnosis and the long-term impact this may have on their quality of life. Convoluted pathways to diagnosis including repeat presentation in GP and secondary care appointment are also a key factor in diagnostic delays.

As outlined in the introduction, the literature review undertaken by MPE found that myeloma is one of the most difficult to diagnose cancers with many patients presenting at least 3 times to a GP before being referred for diagnosis.⁽¹¹⁾ Whilst this is UK based data, a literature review across European countries confirmed the applicability of this data in many countries.⁽¹²⁾

The MPE surveys, focus groups and interviews with patients and haematologists were designed to explore and understand the pathway patients take to diagnosis. Of particular interest is information on where patients present, where they are diagnosed and how long it takes. MPE wanted to understand whether patients experienced delays in diagnosis and what the perceived reason for this was.

DEFINING A “DELAYED” DIAGNOSIS

To assist MPE with the interpretation of the survey data, patients and haematologists were asked about how they might define a delayed diagnosis. They were also asked how they would define a timely diagnosis.

Delayed diagnosis: Most patients and haematologists agreed that delayed diagnosis refers to the severity of symptoms and complications patients present with at diagnosis. It is not about arbitrarily setting a timepoint on a delay. However, they also agreed that the misidentification of myeloma symptoms, repeat presentation in primary care and referral to the wrong

hospital department all negatively impact on patient experience and psychosocial wellbeing and should be considered as part of a definition of a delayed diagnosis. Symptoms and convoluted pathways to diagnosis are therefore central to a definition of a delayed diagnosis.

There were differences in pinpointing a more specific perspective on what constitutes a delayed diagnosis. For example, does it relate to the length of time from first visiting a doctor, the number of specialists they have seen or the number of medical consultations they had.



It is often multiple consultations, not necessarily multiple healthcare professionals that can delay diagnosis. The problem is essentially either getting to the right person the first time or that the physician is not understanding or mistaken in the analysis of why the patient was suffering from symptoms or organ damage related to myeloma.

– HAEMATOLOGIST, FRANCE



Delayed diagnosis is indicated by any significant deterioration of organs or bones and should be avoided. Secondly, patients might have less aggressive myeloma but have common symptoms, like anaemia for 2-3 years. If this wasn't diagnosed as myeloma and should have been and whilst it might not impact on their long-term quality of life, but the patient has spent two years rotating through different doctors and specialities then this constitutes a diagnosis delay, too.

– HAEMATOLOGIST, CZECH REPUBLIC



Delayed diagnosis, I would say, is something where people either have pain or have symptoms which are not explained and seen as a possible myeloma. So, wrong interpretation of results. The most common example is that in Germany you visit the orthopaedic doctors. They interpret things not in the right way or did not think about “oh, let's check also for blood values and possible, leukemic diseases.

– MYELOMA PATIENT, GERMANY

DIAGNOSIS PATHWAY



I would say the time issues are probably a factor of two things. Yes, there is the length of time from first seeing a doctor to getting a diagnosis. But there's also what I personally would judge as did the diagnosis happen in time to prevent something more serious happening? So, did it prevent the fracture, for example as it did with me?

– MYELOMA PATIENT, THE NETHERLANDS



I think that it's not so much a question about timing. It's a question about symptoms. It's difficult to say that it's delayed if, after the first symptoms, you go through six months before you get a diagnosis, and in those six months you're living a normal life, then it's not really late. Except that in many cases, we have these back pain issues which are very, very normal in the European countries. You don't really think about this as being something serious until you all of a sudden have a breakdown of your back. Then all of a sudden it becomes very, very serious. So, it's difficult to use the time as a precise mechanism in saying whether it's delayed or not. It's more a question about the symptoms.

– MYELOMA PATIENT, DENMARK



It's difficult to say, because I have seen patients who have delayed diagnosis, meaning more than six months from the first symptoms... they continue to be on stage one myeloma because... they have no high-risk cytogenetics. So, you understand that it's not only a matter of time, but it has also to do with the characteristics of the disease."

– HAEMATOLOGIST, GREECE

Timely diagnosis: As well as defining diagnosis delays, MPE also asked patients and haematologists to define a "timely diagnosis". As expected, participants expressed that it was the reverse of what patients and clinicians agreed constituted a delayed diagnosis.

Timely diagnosis is therefore the absence of advanced disease, symptoms and complications in patients at

diagnosis. Diagnosis should be a streamlined process, with minimal repeat presentations in primary or secondary care. As part of a timely diagnosis, patients should also be listened to, particularly if they present repeatedly with the same symptoms. Patients are usually aware of changes in their own body and can tell when something is not right for them. However, this needs to be aligned with other factors such as length of GP appointments and availability of diagnostic tests.



I think timely diagnosis is when the disease is not advanced. So, it means that organs are functioning normally and there are no essential changes in person's health or life's routine, a person is independent, can implement every day's activities as usual.

– MYELOMA PATIENT, LITHUANIA



A timely diagnosis is where they haven't yet had any bone damage or significant pain or damage to kidneys or anything that's really kind of making them feel unwell. Then we can identify that they have myeloma and start treatment quickly. That's what you would want to be the pathway - that the first onset of the kind of most minor symptom leads to their diagnosis. The right test that gets you to the right place.

– HAEMATOLOGIST, UNITED KINGDOM



The ideal situation is a diagnosis in the stage we call smouldering with myeloma. Not myeloma, smouldering.

– HAEMATOLOGIST, FRANCE

In line with the last quote from the haematologist, patients who participated in the focus groups who described their diagnosis as timely were often diagnosed first with smouldering myeloma, often when attending a GP appointment for something else. Patients also reported having their myeloma diagnosed whilst seeking help from their GP for another illness or condition.

DIAGNOSIS PATHWAY



I was diagnosed with this smouldering myeloma. I don't think there is any delayed diagnosis with smouldering. If you're diagnosed with a smouldering, you are lucky. And it's usually because of checking something else if there is no damage yet.

– MYELOMA PATIENT, ISRAEL



I go to a doctor, and I told him that I have a little bit pain in my feet because I run a lot. And he took blood tests and after, I think three hours he called me and said "oh, we have to talk".

– MYELOMA PATIENT, GERMANY

DO PATIENTS EXPERIENCE DELAYED DIAGNOSIS?

This research found that, whilst many patients have timely diagnosis, some still experience delays. Patients and haematologists reported that diagnosis can often take more than 5 months and patients often have confusing pathways to diagnosis involving frequent medical consultations and seeing a variety of specialists. Whilst not the predominant place of diagnosis, a higher than acceptable number of patients are being diagnosed via emergency settings.

To assess the European myeloma patient experience of diagnosis, and whether they experienced a diagnosis

delay, the MPE patient survey asked patients the following questions:

- Where did you first present with your symptoms, or receive abnormal blood tests?
- Approximately, how long did your diagnosis take from your first medical consultation?
- Approximately, how many specialists (i.e. doctors) did you see before you had a diagnosis confirmed?
- Where did you have your diagnosis confirmed?

We also asked corresponding questions in the haematologist survey to explore their experience from treating and speaking to myeloma patients.

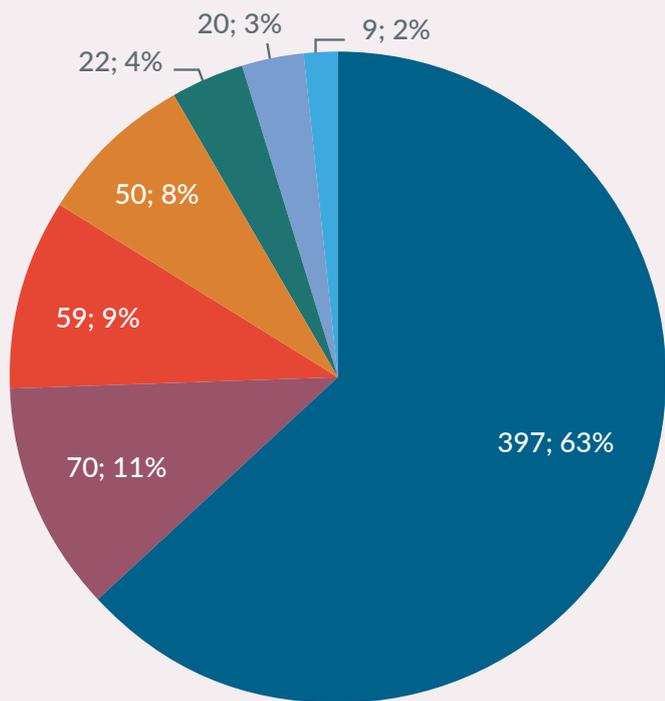
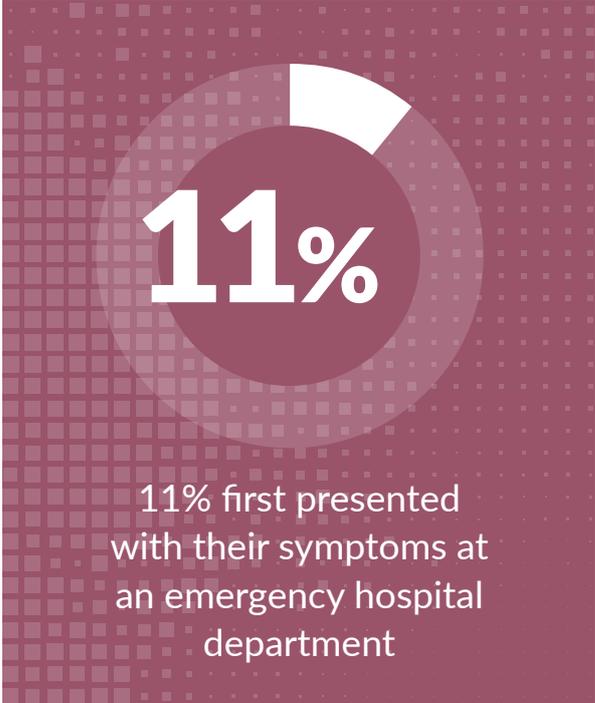
MPE wanted to understand whether patients experienced convoluted pathways to diagnosis, including experience of diagnosis in emergency department, repeat GP visits and referral to the "wrong" hospital departments. MPE also asked both patients and haematologists how they would describe their diagnosis. This was further explored in the qualitative part of the study.

The findings below highlight that in line with the literature and definitions of delayed diagnosis above, many patients experience a delayed diagnosis.

DIAGNOSIS PATHWAY

INITIAL PRESENTATION

The results of the patient survey found that most patients (63%) first present with their symptoms or receive abnormal blood results at their GP. 14% of patients completing the survey presented in a secondary care department, such as a haematology or oncology department. However, 11% first presented with their symptoms at an emergency hospital department. This is concerning as emergency presentation of myeloma has been associated with advanced disease and poorer patient outcomes.⁽¹³⁾ Emergency presentation is potentially related to the risk status of the patient and the aggressive nature of the disease.⁽¹⁴⁾ However, in some cases patients may have waited too long to seek medical help or the diagnosis may have been previously missed in primary care.



Patient responses

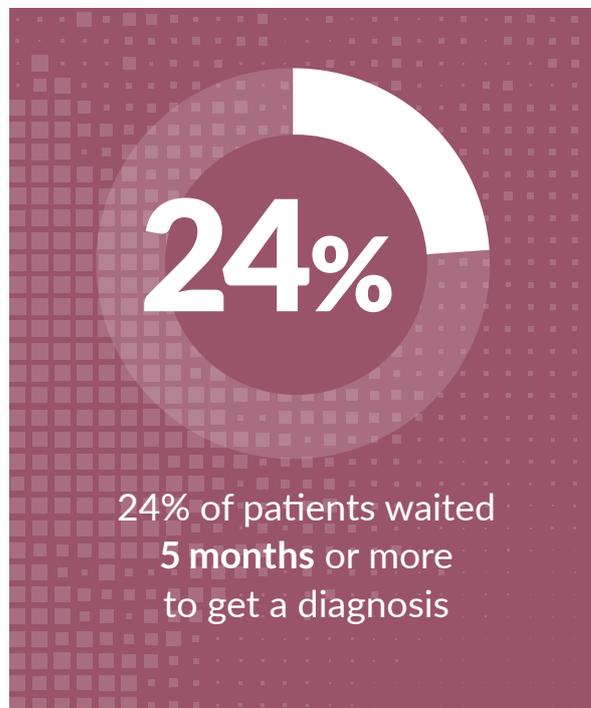
Number and percentage of responses (n ; %) for where patients first presented with symptoms or first received abnormal blood results.

- Specialist myeloma department
- General oncology department
- General haematology department
- Emergency hospital department
- General practitioner (GP) or family doctor
- Other specialist department
- Not sure

DIAGNOSIS PATHWAY

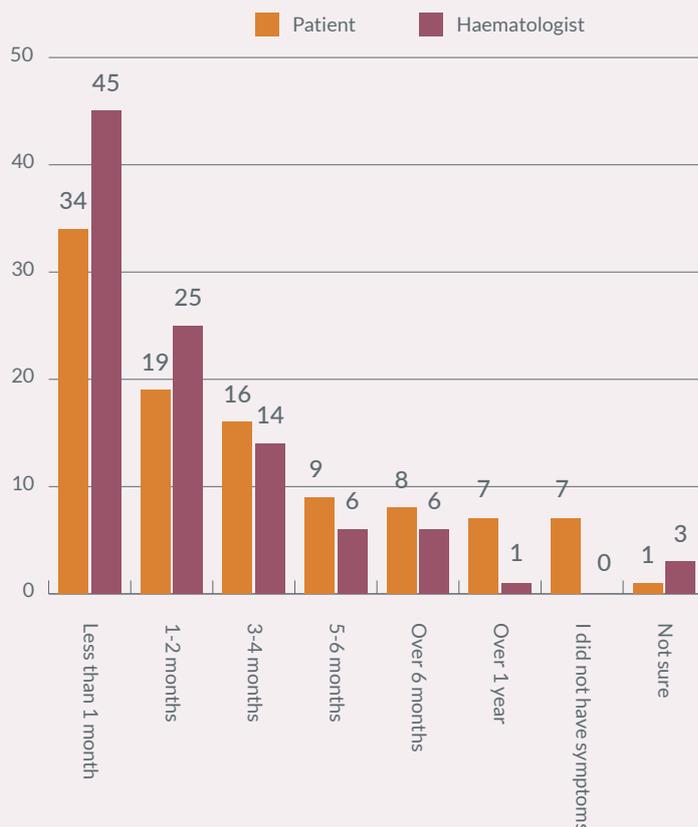
TIME TO DIAGNOSIS

MPE patient survey found that although 34% of patient respondents were diagnosed within a month of consulting a health care professional, 24% of patients waited 5 months or more to get a diagnosis. Haematologists were also asked “On average, in your country, how long does it take for a patient to have a diagnosis confirmed?” Survey responses from haematologists were slightly more optimistic than patients with 45% stating that diagnosis takes less than 1 month and 13% stating it took 5 months or more. However, both sets of responses highlight that patients do frequently experience lengthy periods before being diagnosed. One of the factors behind this may be referral to the wrong hospital department and numerous hospital visits before having a diagnosis confirmed.



Patient responses

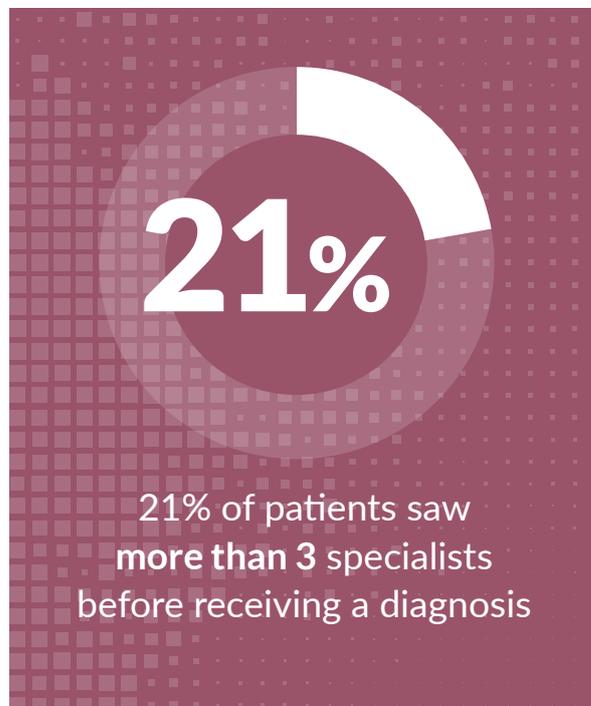
Percentage of patient responses for how long it took them, from first medical consultation, to get a diagnosis versus the percentage of clinician responses for how long it takes on average for a patient to have a diagnosis confirmed in their country.



DIAGNOSIS PATHWAY

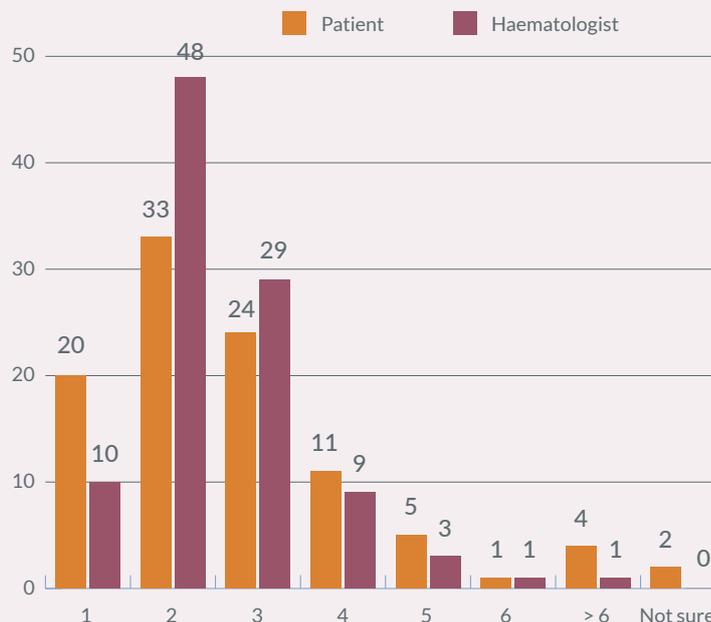
REFERRAL AND MEDICAL CONSULTATIONS

As the literature highlighted, patients report confusing pathways to diagnosis. Given the non-specific symptoms (e.g. bone pain and kidney problems), patients may be misdiagnosed with more common conditions at first or be referred to a speciality such as orthopaedics or nephrology, before finally seeing a haematologist.⁽¹⁵⁾ Anecdotally, MPE hears that patients may be referred back to primary care after every secondary care appointment, adding to the time it takes to diagnosis. In the MPE patient survey results, most patients saw up to 3 different specialists before receiving a diagnosis, however 21% of patients saw more than 3. 4% of patients saw more than 6. Haematologists were also asked a corresponding question “On average, how many specialists do you think patients see before being diagnosed?” Their responses were slightly lower than patients, with 14% stating patients saw more than 3 specialists. Within the context of the survey, the term specialist referred to primary and secondary care doctors from different specialisms such as general practice, orthopaedics and haematology.



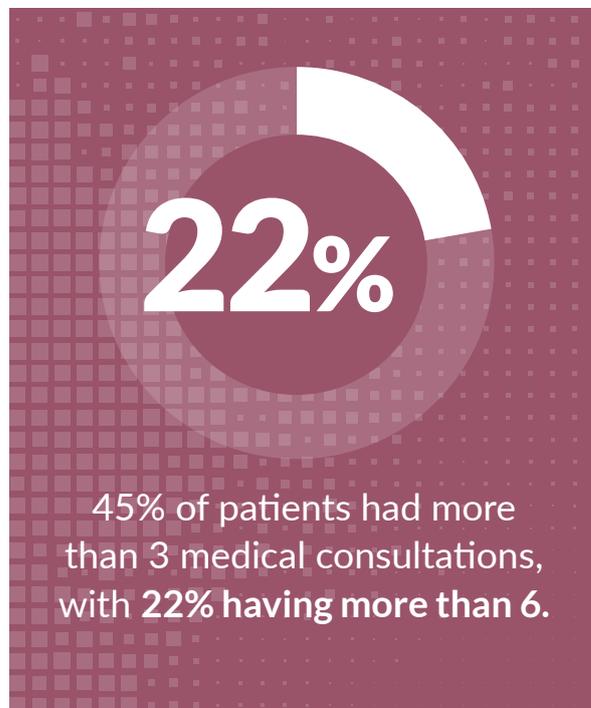
Patient and haematologist responses

Percentage of patient responses for how many specialists they approximately saw before being diagnosed versus the percentage of clinician responses for how many specialists they think a patient sees before being diagnosed.



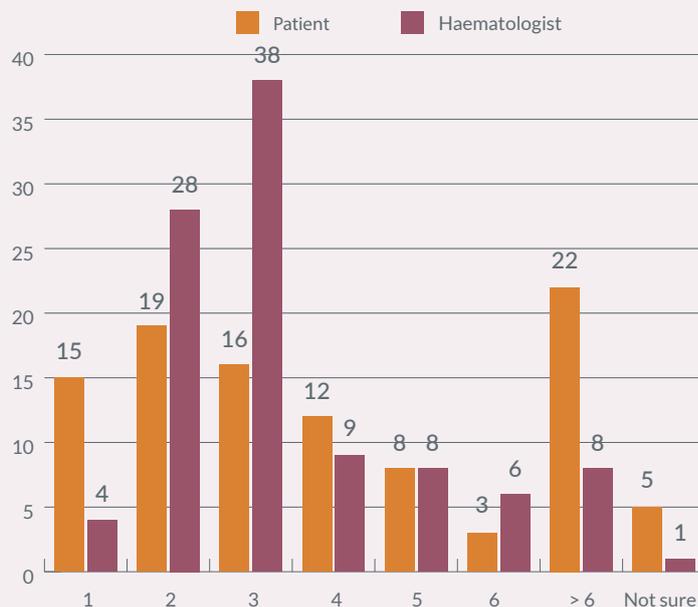
DIAGNOSIS PATHWAY

Similarly, many patients participating in the survey had up to 3 medical consultations before receiving a diagnosis. 45% of patients had more than 3 medical consultations, with 22% having more than 6. Again, haematologists were asked the corresponding question “On average, how many medical consultations do you think patients have before being diagnosed?” Their responses were more or less aligned with patients with 38% reporting that their patients would have 3 medical consultations and 31% stating they would have 4 or more..



Patient and haematologist responses

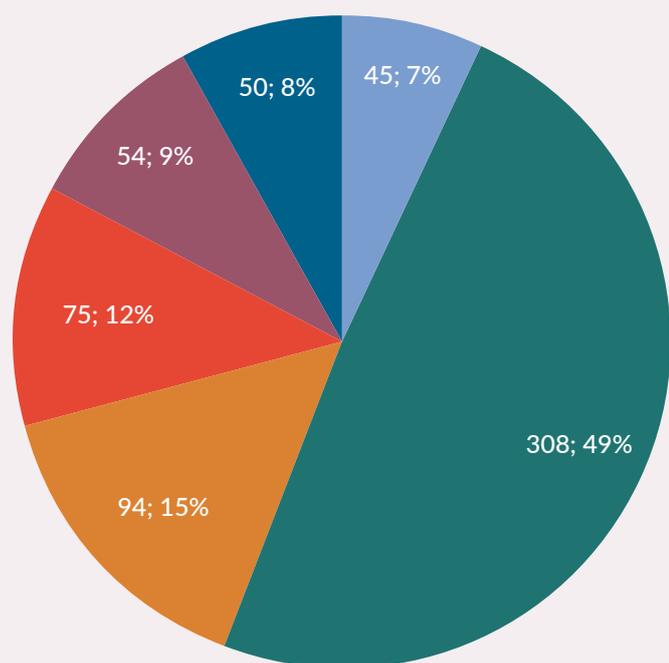
Percentage of patient responses for how many medical consultations they approximately had before being diagnosed versus the percentage of clinician responses for how many medical consultations they think a patient has before being diagnosed.



DIAGNOSIS PATHWAY

LOCATION OF DIAGNOSIS

The patient survey found that most respondents received their diagnosis in a general haematology department (49%), general oncology department (15%) or a specialist myeloma department (12%). 9% of patients received their diagnosis in an emergency department, aligning to the question on initial presentation. 8% were diagnosed in another specialist department, again confirming that some patients are referred to a speciality that is different to haematology.



Patient responses

Number and percentage of responses (n ; %) for where patients had their diagnosis confirmed.

- Emergency hospital department
- Specialist myeloma department
- General oncology department
- General haematology department
- General practitioner (GP) or family doctor
- Other specialist department

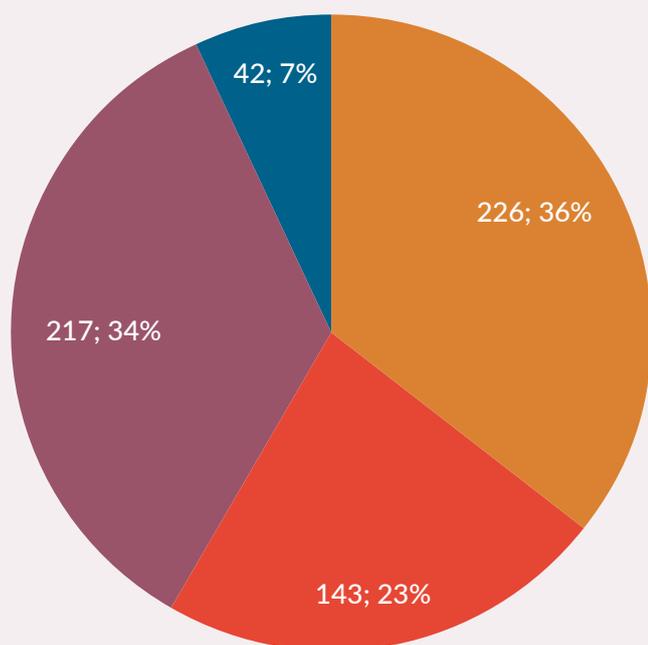
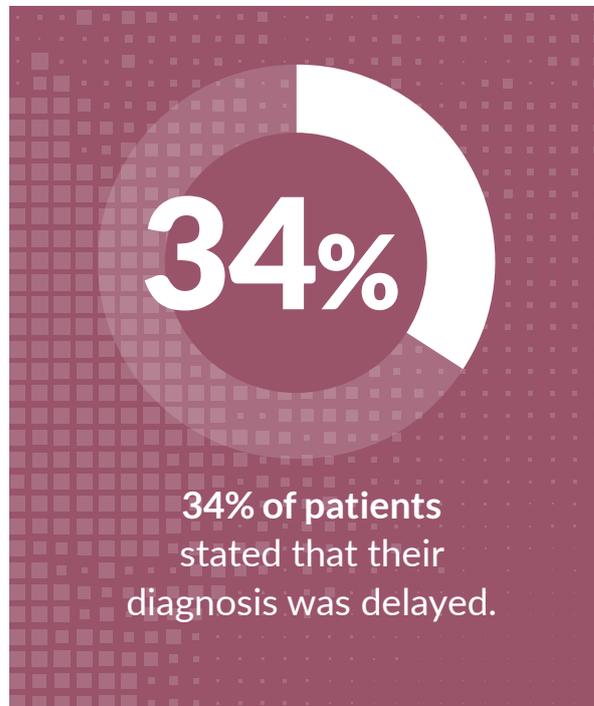
DIAGNOSIS PATHWAY

PERCEPTIONS OF DIAGNOSIS DELAYS

Whilst the above results on the location, timing and the medical consultations experienced as part of a diagnosis point to diagnostic delays, without detailed information on the specific context it can be difficult to confirm that a patient has experienced a diagnostic delay.

Patients were therefore asked how they would describe their diagnosis. It is positive to see that many patients (36%) thought they were diagnosed in an early or timely way, and many (23%) described their diagnosis as neither early nor late. However, 34% of patients stated that their diagnosis was delayed.

Patients with a prior diagnosis of smouldering myeloma were more likely (71%) to state they were diagnosed in an early/timely way – this is likely to have been as it was picked up incidentally or without serious symptoms. Patients without a prior diagnosis of smouldering myeloma were more likely to report their diagnosis as delayed with 30% stating that were diagnosed in an early or timely way and 39% reporting a delayed diagnosis.



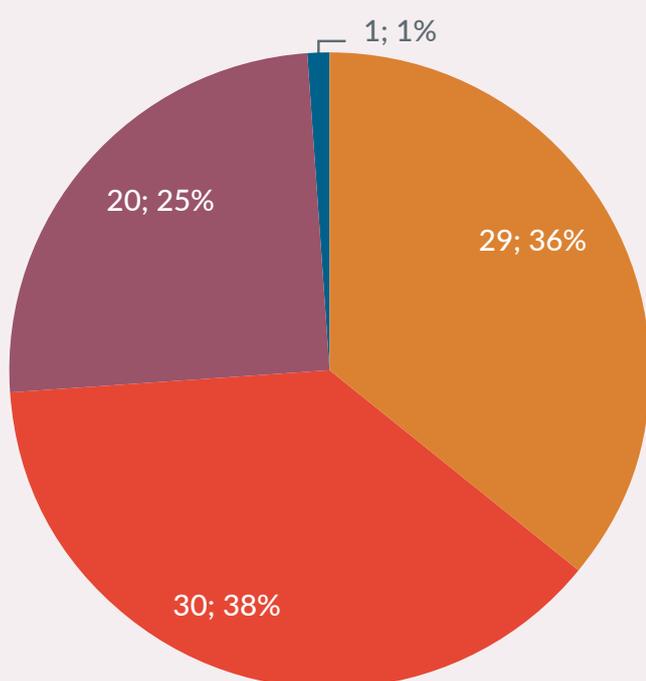
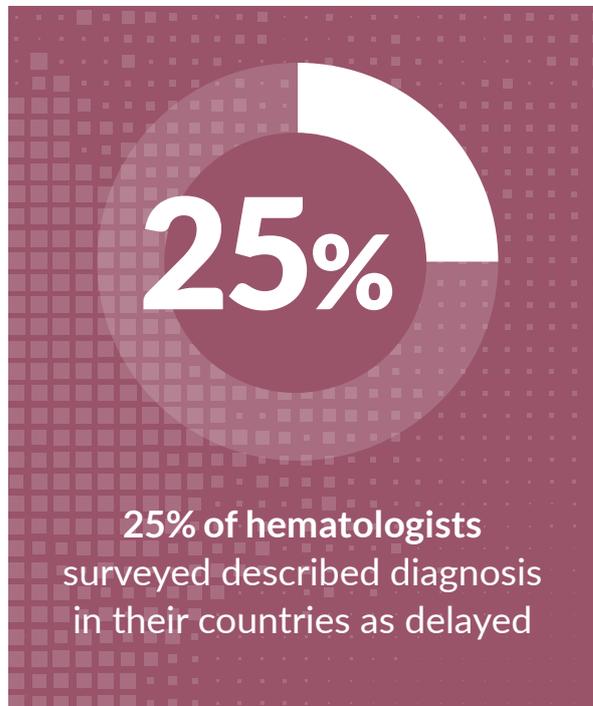
Patient responses

Number and percentage of responses (n ; %) for how patients would describe their diagnosis.

- Not sure
- Delayed
- Neither timely nor late
- Early/timely

DIAGNOSIS PATHWAY

Haematologists were also asked the question “On average, how would you describe the timing of diagnosis in your country?” 36% described it as early/timely and 25% as delayed. This was followed up with the question “On average, how often do you see patients who are diagnosed late?” 28% said that very few patients were diagnosed late.



Haematologist responses

Number and percentage of responses (n ; %) for how clinicians describe the timing of diagnosis in their country.

- Not sure
- Delayed
- Neither timely nor late
- Early/timely

DIAGNOSIS PATHWAY

Nearly 50% of haematologists said they sometimes saw patients who are diagnosed late, 16% and 9% stated that often or most of their patients were diagnosed late. Whilst this study was not designed to compare country specific data, it would be interesting to further explore the specific countries which reported higher rates of delayed diagnosis.

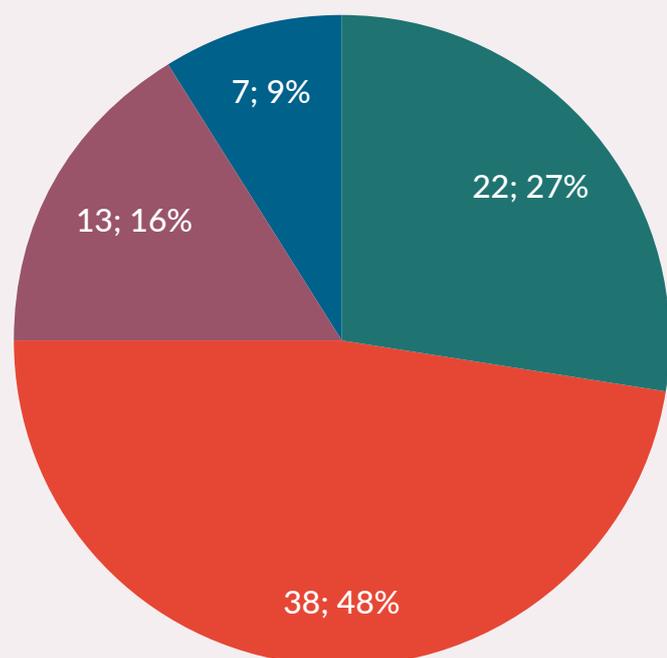
DISCUSSION

In Europe, our findings show that patients often experience early and timely diagnosis.

However, they also show that many myeloma patients experience delays in diagnosis, aligned to the findings from the literature review and meeting the criteria of

definition of delayed diagnosis generated from the focus groups and interviews. It is clear from the findings that pathways to diagnosis can be convoluted and potentially confusing to patients. Some patients are also diagnosed with symptoms and complications impacting on their quality of life.

It is important to understand why patients are experiencing these delays and as a community discuss how we design solutions to address them. Our data also represents a snapshot of patient and haematology perspectives on diagnosis, further country specific data and evidence needs to be generated by policy makers and advocates to understand situation and where to target solutions.



Haematologist responses

Number and percentage of responses (n ; %) for how often clinicians see patients who are diagnosed late.

- Most of my patients have a delayed diagnosis
- Often, more than half of my patients have a delayed diagnosis
- Some of the time, less than half of my patients have a delayed diagnosis
- Very few patients have a delayed diagnosis

BARRIERS TO TIMELY DIAGNOSIS

TO SUPPORT THE SURVEY RESULTS, THIS RESEARCH FOUND SEVEN CORE THEMES FROM PATIENTS AND HAEMATOLOGISTS CONTRIBUTING TO DELAYED DIAGNOSIS IN MYELOMA.

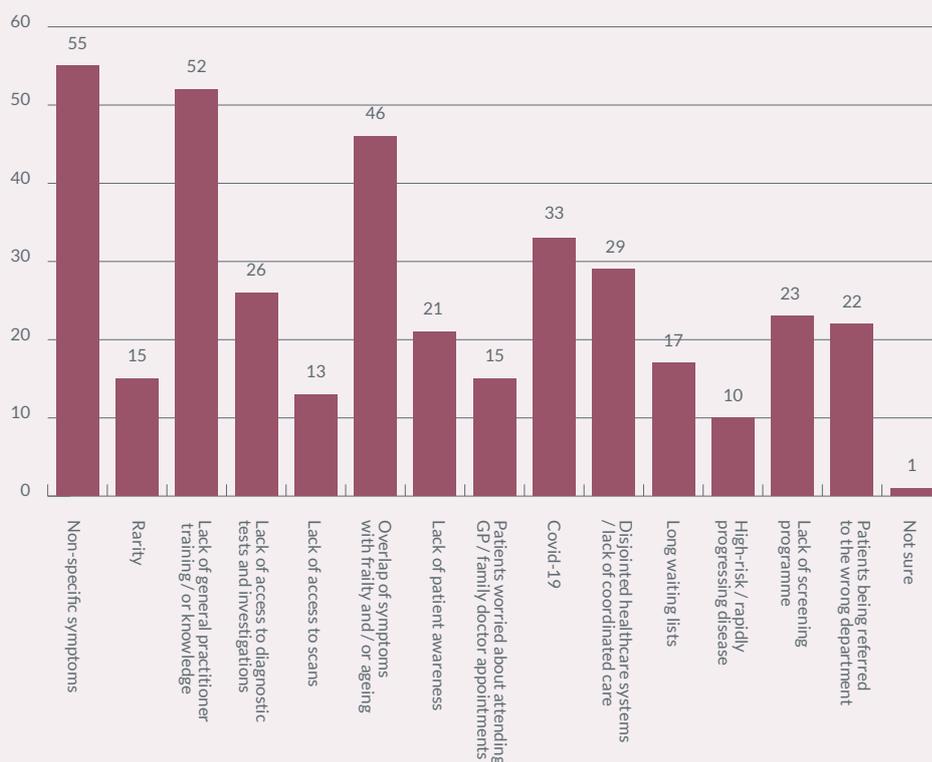
Barriers often relate to the rarity of the disease and the non-specificity of symptoms. Patients are often not diagnosed until something serious happens (such as fractures), or they are referred to the wrong hospital department for treatment of a specific symptom (such as kidney or bone problems). Other barriers relate to geographical inequalities, health system related factors such as inadequate resourcing, and availability and length of GP appointments. Covid-19 has exacerbated delays in the system for patients.

To understand why delays in diagnosis occur, the survey with haematologists asked, “What do you consider the biggest barriers to early diagnosis?” Results found that the non-specificity of symptoms (69%), their overlap with more common signs of frailty/ageing (57%) and lack of GP awareness of myeloma (65%) were the main reasons perceived behind the diagnosis delays amongst participants. 41% of haematologists raised Covid-19 as a central reason for delays. Health system and access

issues were also commonly cited barriers to timely diagnosis, including disjointed healthcare systems and lack of coordinated care (36%) and lack of access to diagnostic tests and investigations (33%). 28% outlined that a barrier is patients being referred to the wrong hospital department. These are all issues we discussed with patients and haematologists in the focus groups and interviews. Their perspectives are outlined in the section below.

Haematologist responses

Number of haematologist responses for what they consider the biggest barriers to early diagnosis are.



BARRIERS TO TIMELY DIAGNOSIS

THEME ONE: RARITY OF MYELOMA AND NON-SPECIFICITY OF SYMPTOMS

Myeloma is a rare and incurable cancer. Given its rarity, GPs are only likely to see around 2 myeloma patients in their career. This means GPs are unlikely to have experience in diagnosing myeloma, which both haematologists and patients raised as a core theme in the discussions.



The story is more or less the same all across the board, that the doctors are not aware of this illness.

– MYELOMA PATIENT, DENMARK



My GP said, you know I have to tell you, you are my first myeloma patient. Wow. I have never seen a myeloma patient before you.

– MYELOMA PATIENT, UNITED KINGDOM



We must remember that myeloma is a rare disease, a very rare disease. In fact, a GP will probably treat or see among his patients one or two myeloma patients in his whole career

– HAEMATOLOGIST, FRANCE

It was agreed by most participants that the rarity issue is compounded by the non-specific presenting symptoms, the most common of which include fatigue, bone pain, back pain, recurrent infections, and kidney problems. GPs suspecting myeloma and ordering the correct tests when a patient first attends a GP appointment, was outlined as unlikely.

In most cases, presenting with symptoms of myeloma are more likely to be more common conditions. Participants understood the issues faced by GPs in primary care and why myeloma is sometimes missed. However, some

patients did report a feeling of being frustrated and not listened to when their GP did not follow up with further tests and investigations. Particularly as they felt a negative change in their health indicating something was seriously wrong.



I went to a new GP, and he asked me about my symptoms... I told him 'I'm so tired all the time', which was nothing new... I have been always tired. This was the first time somebody took my tiredness seriously'

– MYELOMA PATIENT, GERMANY



I think the problem is people who are diagnosed with myeloma are generally the older age group. And so, there is that possibility that patients put down some of the symptoms to old age.

– MYELOMA PATIENT, DENMARK



I think the main barrier is that, to some extent, it is a rare disease and incidence of it is not so high plus the symptoms are not unique for this disease. So back pain is a general symptom and 70% of people have sometimes some back pain.

– HAEMATOLOGIST, CZECH REPUBLIC

The common symptoms also mean it may be difficult for patients to suspect they have something too, which might delay them presenting in the first place.



Patients also think, "oh, it's only neck pain, nothing special. I can go into a pharmacy and get some ibuprofen or whatever".

– MYELOMA PATIENT, GERMANY

BARRIERS TO TIMELY DIAGNOSIS

Whilst myeloma is predominantly a disease affecting people over 65, a high proportion of younger myeloma patients (under 60) participated in the focus groups and interviews. Younger patients interviewed raised the issue that their myeloma may have been missed as they didn't "fit" the age profile associated with the disease, which is typically over 65.



There was a reluctance for haematologist to say that this is multiple myeloma. It is possible he didn't want to give me that diagnosis. And perhaps it's because I was relatively young at 42 at the time, very active and in a very demanding position

– MYELOMA PATIENT, UNITED KINGDOM



I had a broken rib, and I went to the doctor. He said, It's impossible. You're too strong, you're too young he didn't want to send me for more research. And then six months later I just collapsed.

– MYELOMA PATIENT, BELGIUM



When my symptoms started, I immediately was seeking medical help. However, it took a long time to get a diagnosis. I experienced many bone fractures, I was not able to walk for half a year, I needed to learn to walk again. I think this happened because of a few reasons – the disease is rare, and my age was not typical for myeloma. Therefore, doctors did not know what to look for and it took longer to find the reason for my symptoms

– MYELOMA PATIENT, LITHUANIA

It is important to reflect here that participants and MPE acknowledged the difficulties faced in diagnosing myeloma and that GPs are not at fault. In fact, they perform a vital service for patients which is well regarded. It is more about recognising the challenges and patient experience to begin a discussion about potential solutions.

3 haematologists raised the short amount of training that doctors might receive in medical school as a factor in the GP awareness, which is understandable given its rarity and the number of conditions they need to know about.



Doctors are quite aware of what myeloma is but probably less so about amyloidosis, because it's a very rare disease and it's barely taught in medical school.

– HAEMATOLOGIST, FRANCE



I think it's a standard part of the educational program for students. It's a limited amount of time, definitely. It's not too robust, but it is okay. You learn about this diagnosis during medical school but then you probably diagnose one patient per 10 years, so it's very difficult to know.

– HAEMATOLOGIST, CZECH REPUBLIC

Additional factors that impact on a patient being diagnosed late is to do with non-secretory disease which is not picked up in initial tests and investigations, making diagnosis a lot more difficult. Whilst rare, this was raised by two patients from the focus groups. This is an additional factor GPs need to be aware of when considering myeloma.



From February until I was diagnosed in May, I had increasing pain in my back. I just went to my diaries, which are quite detailed in that period, and it was quite horrendous to read the things I went through during those months because nobody was able to figure out what was wrong because there were no elevated levels. The usual criteria didn't apply. There was nothing to see there. The blood was as expected, no elevated levels of those things that you usually look for, but my back just broke down and I was picked up by an ambulance. And when I entered the hospital, I was diagnosed within 5 hours.

– MYELOMA PATIENT, DENMARK

BARRIERS TO TIMELY DIAGNOSIS

THEME TWO: REFERRAL TO WRONG DEPARTMENTS

The literature review, and the survey findings highlighted that patients may see numerous specialists and attend many medical appointments prior to being diagnosed with myeloma. Exploring this issue further, the focus groups and interviews confirmed that patients do experience convoluted pathways to diagnosis. Renal clinics, orthopaedic clinics and physiotherapy clinics were cited as departments often visited by patients.



When you are in that situation you are totally in the doctor's hands. If you are told this is a kidney problem, and you will control it with that little pill you don't even think there's anything else. I asked if I would need dialysis or a kidney transplant. I thought all my problems came from the kidney and the disease was located there, but she never said "look there is a possibility of having myeloma and it might be an haematological disease" and such. I lost a year thinking I had a kidney problem.

– MYELOMA PATIENT, ISRAEL



If a patient had renal failure the GP would refer the patient to a nephrologist to take care of them. Even the nephrologist, despite the concentration of patients who attend this clinic, would not necessarily think it could be myeloma.

– HAEMATOLOGIST, CZECH REPUBLIC

THEME THREE: HEALTH SYSTEMS SOURCE AND STRUCTURE

Discussions raised that delays in diagnosing myeloma can also be caused by healthcare system factors. Funding, resource, and staffing shortages can mean delays to GP appointments, longer waiting times for patients being referred, or that GPs are overworked and overstretched in their roles. Many participants described the strain their healthcare systems are in, which was already profound in some countries and made worse by COVID-19.



...because of the pressure that GP is under, I suspect a number of things can be missed. In some areas they even tell you, okay, if you have two different symptoms, you need two different appointments, so you cannot go in and say my knee is hurting me, but also my back is hurting me...

– MYELOMA PATIENT, UNITED KINGDOM



To my mind, the main reasons could be long waiting times to get to specialists.

I think the biggest issue is in the first link of the medical system. GPs are overloaded with bureaucracy, they became clerks when they should be doctors and instead of time they could give to patients in order to go through symptoms or problems systematically and carefully, they must fill all these forms and write notes. Maybe, if there is an adequate consultation time, people will experience better health care. But this is in the governmental level to solve this problem.

– MYELOMA PATIENT, LITHUANIA

The haematologist survey found that 36% of respondents felt that lack of coordinated care was an issue within their health system for timely diagnosis. It was agreed by some patients that a lack of coordination in healthcare systems, between primary and secondary care and also between secondary care institutions can be an issue for patients as test results and patient notes may not be shared between institutions. This can potentially impact on timely diagnosis.



The problem is that [the hospitals] have different systems and their systems don't talk to each other. So, when I go to my haematologist here at my own home city, all the things that she wrote down in their system don't talk to the university hospital system.

– MYELOMA PATIENT, FINLAND

BARRIERS TO TIMELY DIAGNOSIS

THEME FOUR: SHORT AND UNAVAILABLE GP APPOINTMENTS

It was raised by both patients and haematologists, that delays to patients attending GP appointments (such as waiting time for an appointment) and the length of time patients spend with a GP, are potential contributing factors to diagnosis delays. These challenges are most often not the fault of GPs, rather, they are related to policy decisions and resource constraints.

Many countries, like the UK and Finland, have designated time slots for appointments which last around 10 minutes. Participants raised the fact that this is a very short time period for patients to present symptoms and for the doctors to assess whether the patient has a serious condition. Payment schemes in some healthcare systems (e.g. payment per patient appointment), incentivise shorter and more rushed hospital appointments.

Other participants stated that a shortage of GPs was causing long waiting times, particularly in France. Recruitment to GP posts is becoming more difficult and there are many vacant positions, impacting on the ability to get GP appointments in the first place.



Having only 5 - 10 minutes to see a patient, I do not think is enough to come to a diagnosis with the complexity of multiple myeloma.

- MYELOMA PATIENT, UNITED KINGDOM



10 minutes or 12 minutes, it's a tiny amount of time to actually think through a patient's symptoms, think what tests you want to request and actions you want to take for a patient. So, I do think that contributes to barriers in all cancer diagnoses.

- HAEMATOLOGIST, UNITED KINGDOM



And today there are very few GPs in France. And my patients have difficulties when their GP is retiring to find a new one and this is in downtown Paris. So, when you're outside Paris, it's, it's even worse. So this is a real issue in France.

- HAEMATOLOGIST, FRANCE

When calling GP practices to arrange appointments, there might also be difficulties in getting emergency GP appointments as the non-specific symptoms of myeloma do not sound like a medical emergency. This is particularly difficult over COVID-19 where many GPs have less appointments per day, longer waits and are triaged via telephone before attending a face-to-face meeting.



So, if you're calling up to make an appointment, you say, well, something hurts and I'm a bit tired. You might see a doctor in three or four weeks.

- MYELOMA PATIENT, UNITED KINGDOM

As patients may experience delays in accessing a GP appointment, some participants revealed that they decided to seek assistance privately. However, this poses potential inequalities as only those who can afford private healthcare can choose this avenue.



I decided to just go privately to see a haematologist who at the first meeting said it's highly probable that you have myeloma. And they referred me to their oncology hospital, haematology oncology hospital. But it was only because I had this private insurance. Otherwise, I think my path would have been much, much longer and painful.

- MYELOMA PATIENT, POLAND

BARRIERS TO TIMELY DIAGNOSIS



It is the approach of authority in health care system. And the worst situation is for those people who do not have enough money and cannot do some additional tests or consultations.

– MYELOMA PATIENT, LITHUANIA



When we were confined it was difficult, the patient could not see the physicians or go to the emergency room. But most of the population was not confined during COVID. So then the population should have had access to a general practitioner normally. However, I agree it was not the case and that has been a big problem.

– HAEMATOLOGIST, FRANCE

THEME FIVE: COVID-19

41% of haematologists raised COVID-19 as a big factor in diagnosis delays and it was raised as an exacerbating factor to delayed diagnosis by a number of participants. Issues with delayed diagnosis existed before the pandemic and have been compounded by it.

Generally, barriers were felt during the initial lockdowns and longer term consequences were raised due to the backlog of patients. More haematologists raised it as an issue compared to patient participants.

Some patients commented that as their diagnosis happened some years ago and they couldn't fully comment on the impact COVID-19 was having on patients now.



This cannot be proven but it is my opinion that a lot of patients evaded going to the doctor as an option when they had problems due to COVID. We have had maybe more advanced cases of myeloma diagnosed than usual.

– HAEMATOLOGIST, NORTH MACEDONIA



I think COVID definitely played a general role in the last two years. We will see what's happening now because a new wave is coming. It definitely played a role because there was some hesitation to even go outside home and to visit the doctor. So definitely but it was for all diagnosis, I suppose.

– HAEMATOLOGIST, CZECH REPUBLIC



Seeking a GP has been harder, more difficult. So, on top of the trouble that's already there, the trouble around COVID 19 has added to that. So, it must have been terribly harder.

– MYELOMA PATIENT, GERMANY

THEME SIX: GEOGRAPHICAL INEQUALITIES

Discussions raised the issue of “location” as being a factor in timely or delayed diagnosis. It was largely agreed that patients who live in big cities, with large populations and access to expert disease centres, are more likely to be diagnosed quicker.

It was felt that GP practices in big cities had more exposure to myeloma and were more likely to suspect it. GP practices were larger and could recruit and retain staff more easily, so it wasn't as difficult to get an appointment. Patients also did not have to travel to attend a GP appointment, so were more likely to arrange one earlier.

BARRIERS TO TIMELY DIAGNOSIS



If you live in city centres, where GPs have more than a few patients, they might think of it. But if you live in the country part, no, they don't think about it or they are not well enough instructed to look for it.

– MYELOMA PATIENT, BELGIUM



How many cancer patients does a GP actually see? Very few, I should think. I live in Paris, so it's big and we have specialist institutions, but if you're out in the country somewhere, you're not going to get that kind of quality care.

– MYELOMA PATIENT, FRANCE



The specialist units are located in big cities. So, people who live far away, well, they can experience longer delays.

– MYELOMA PATIENT, POLAND



It seems to be more and more true, particularly in the very remote part of France, where there is no more general practitioner or your general practitioner is 70 to 100 kilometres from where you live.

– HAEMATOLOGIST, FRANCE

THEME SEVEN: ACCESS TO TESTS AND INVESTIGATIONS

As well as geographical inequalities within countries, there are differences between countries in health system funding, structure and resource. While the express differences between health systems was not a central feature of this study, 33% of haematologists felt that access to diagnostic tests was an issue impacting on delays with 13% citing delays caused by a lack of access to scans.

Exploring the topic of access to tests in GP practices

within the patient focus groups and interviews did not highlight many access issues. Most patients and haematologists said there were no access issues. However, undertaking the correct tests in the first place was deemed a more important factor.



... as far as I know, for example, electrophoresis is not an expensive test, but because the GPs don't have the knowledge, they don't run these tests. So yes, I think there is an access issue .

– MYELOMA PATIENT, POLAND

The lack of discussion on access to tests might be related to the availability of tests in clinics and their relatively low cost. It might be related to lack of information and knowledge of the tests and investigations that are specifically available in primary care and also the fact most participants were from countries with high GDP and GDP expenditure on health. This is an issue that might benefit from further and more targeted research, including countries from more diverse parts of Europe.

The one variation in access that was raised in a patient focus group was access to different scanning techniques, such as CT/PET scans and MRI scans used to confirm diagnosis and understand the myeloma. It is not clear how widespread this issue is, however, as with access to tests in GP practices this should be explored further. One haematologist also raised access to PET scanning as an issue in North Macedonia.



What is the best tool to use for the diagnosis? Is it the CT, the PET or the MRI? As far as I know, it should be either MRI or PET, or CT. But I heard that some newly diagnosed patients are sent to CT and then nothing is seen there and until they go to another doctor or another medical centre and then they are sent to different one, or to the correct one, and then their new diagnose is now correct.

– MYELOMA PATIENT, ISRAEL

BARRIERS TO TIMELY DIAGNOSIS



Yes, we do have access to PET scanning and have for the last five years or so. But it's in a formal investigation which has still not been approved for myeloma patients. We're mainly using them for Hodgkin's and for non-Hodgkin lymphoma. Nevertheless, we are kind of using good relations with the pet centre to eventually send them one or two myeloma patients in a month or so.

– HAEMATOLOGIST, NORTH MACEDONIA

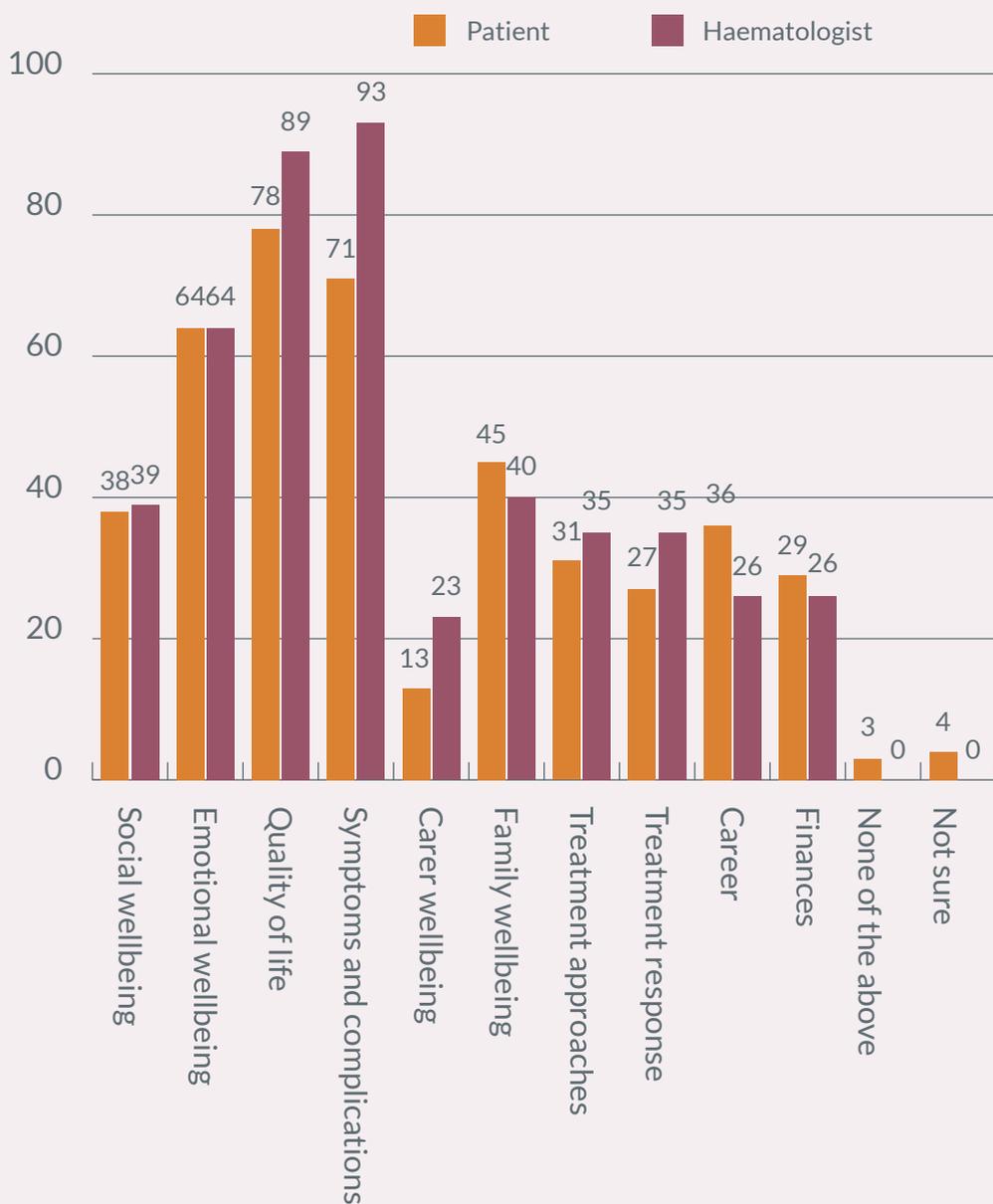
While this issue was not explored in depth, GP awareness about the appropriate tests to conduct and when, and improving access to different types of tests, both play a role in timely diagnosis. Further research on these topics should be conducted to better understand how to increase education around available diagnostics and the accessibility landscape of relevant diagnostic tests in Europe and how to expand this.



As well as geographical inequalities within countries, there are differences between countries in health system funding, structure and resource.

IMPACT OF A DELAYED DIAGNOSIS

IN THE PATIENT SURVEY, WE ASKED PATIENTS WHO HAD EXPERIENCED A DELAYED DIAGNOSIS “WHAT AREAS OF YOUR LIFE WERE AFFECTED BY A DELAYED DIAGNOSIS?”. SIMILARLY, WE ASKED CLINICIANS, “WHERE A DIAGNOSIS IS DELAYED, WHAT AREAS/DOMAINS ARE IMPACTED FOR THE PATIENT?”. THROUGH THE QUALITATIVE INTERVIEWS, THIS RESEARCH IDENTIFIED 6 CORE THEMES ON THE IMPACT OF A DELAYED DIAGNOSIS.



Percentage of patient responses for what areas of their lives were impacted by a later diagnosis versus the percentage of Haematologist responses for what areas/domains are impacted by a patient’s delayed diagnosis.

IMPACT OF A DELAYED DIAGNOSIS

THEME ONE: LONG-TERM SYMPTOMS AND COMPLICATIONS

The key theme highlighted by most participants, supporting the results of the survey, was that a delayed myeloma diagnosis can lead to the development of complications, such as fractures, spinal cord compression and renal failure. These can prevent optimum treatment and impact on quality of life of patients.

Patients and haematologists outlined that serious symptoms and complications at presentation can have a lasting and irreversible impact on patients and may not always be resolved by effective treatment. This aligns with the definition of delayed and timely diagnosis outlined above.



The problem with taking a long time to diagnose is that so much damage is done to your vertebra and then ribs broken and so on. And that damages you for the rest of your life.

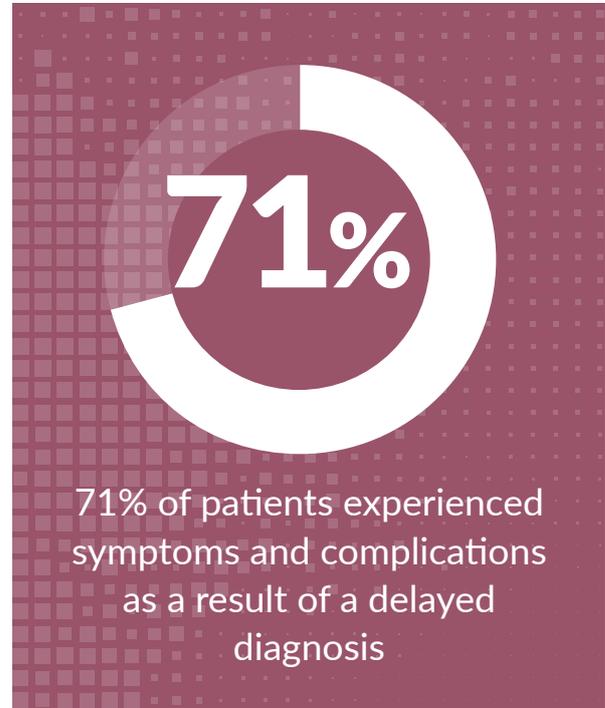
– MYELOMA PATIENT, BELGIUM

Our survey revealed that 71% of patients experienced symptoms and complications as a result of a delayed diagnosis. Similarly, 93% of clinicians agreed that symptoms and complications were one of the main areas impacted by a delayed diagnosis.



I was very ill from the beginning, so I was vomiting, I couldn't go up the stairs anymore, I had pain in my bones. The specialists didn't do anything about it, so I became progressively worse. My kidney function hasn't been normal since, because for months it was deteriorating because they were not looking in the right place and that was the job of a specialist.

– MYELOMA PATIENT, BELGIUM



I actually have a 67% disability. I have been walking for two weeks, I have been in a wheelchair twice, more than 15 months each time, with immobility. In other words, lying on a bed or moving in a wheelchair, because it first attacked my back. Myeloma, then attacked my knee and made a 20 centimetres hole in my femur. I have put a mega prosthesis on my left leg and that's where I am at now, with a fissure trying to recover, walking with a walker and only for a short distance. If this had been done before, I'm sure I wouldn't have had so many problems.

– MYELOMA PATIENT, SPAIN



I went down 15 centimetres in height, I was 1,87 and now I am 1,72. And it's because the vertebrae were crushed one on top of the other so it's impossible to live without any pain.

– MYELOMA PATIENT, ISRAEL

IMPACT OF A DELAYED DIAGNOSIS



So the main impact is their burden of the symptoms, I think. So that the later the diagnosis is made, then patients are more likely to have more significant pain or more other symptoms associated with their myeloma, which then make it harder for them both in terms of suffering through that initial diagnosis and then also tolerating the treatment as it starts.

– HAEMATOLOGIST, UNITED KINGDOM



One patient, who was a taxi driver, he had back pain for six months, his GP gave him painkillers and after six months, he landed in the emergency department because he had kidney failure. So the diagnosis was not done for six months. When you have kidney failure, this is serious, and it jeopardizes your potential, future treatments. This is one potentially very severe consequence of a delayed diagnosis. The other one, of course, is about bone lesions and medullary compression, you may end up paraplegic, and so this is also extremely serious. So, if you're too late, you may experience one of these two major issues.

– HAEMATOLOGIST, FRANCE

THEME TWO: DIFFICULTIES UNDERTAKING NORMAL DAILY ACTIVITIES

A patient specific issue raised by patients participating in the focus groups, who had a direct experience with a delayed diagnosis, felt this had impacted their ability to do “normal daily activities”. Both the short- and long-term symptoms and complications they were experiencing from a delayed diagnosis impact on their ability to exercise, walk and do activities they enjoyed before being diagnosed with myeloma.



In my case, the myeloma is in remission and its great, but I still have a lot of lesions in my body. So, for me that is because my diagnosis was late. In other words, even if myeloma is more or less “solved”, and the haematologist tells me everything is phenomenal, I still have to wear fentanyl patches and my back still hurts and I'm afraid to get on a bike.

– MYELOMA PATIENT 54, SPAIN



It was a full year of steadily decreasing blood results, and fatigue before I was diagnosed. I couldn't move around. I could walk, but I couldn't walk uphill without frequent stops to have a rest. And that just wasn't me. There was something seriously wrong. I knew there was something seriously wrong. And it took a long time before that was recognized. In fact, I would say that my red blood count was down at 8.3 when I was diagnosed. And I found out later that I was at serious risk of having a stroke with levels like that.

– MYELOMA PATIENT 75, UNITED KINGDOM



If their symptoms have affected their mobility or that their pain is preventing them from getting out and about and seeing family and friends, then all of those things have a massive impact on quality of life.

– HAEMATOLOGIST, UNITED KINGDOM

IMPACT OF A DELAYED DIAGNOSIS

THEME THREE: IMPACT ON QUALITY OF LIFE AND EMOTIONAL WELL-BEING

In the survey, focus groups and interviews patients and haematologists agreed that a delayed diagnosis can have a detrimental and lasting impact on aspects of their quality of life, social and emotional wellbeing. The late diagnosis, combined with the type of diagnosis (an incurable cancer), mean it is particularly burdensome for patients and their families.



To me, it's all about quality of life and considering that, you know, there is no cure for our diagnosis. So, what you want to make sure is that you have a good quality of life, and so a late diagnosis will impact on that. Now, that covers everything from pain to employment, to mobility.

– MYELOMA PATIENT, UNITED KINGDOM



Looking at those markers of quality of life and symptoms and emotions, I mean, I was definitely not feeling well. Quality of life was very, very low. The symptoms were, you know, I was immobilized. I thought I was going to die.

– MYELOMA PATIENT, DENMARK



I think it impacts everything. It impacts the family wellbeing. It impacts the emotional wellbeing, the social wellbeing, the quality of life, how you basically discuss and live with your friends, with your family. Because you are in an absolutely uncertain situation. What do you do? You cannot sleep. It's really hard, until you have the information. Sometimes it's better to have the information. Then you know, "okay, it's that". If you don't know what it is, that is something which is really very poor for people.

– MYELOMA PATIENT, GERMANY



100% of the patients that come see me delayed or not delayed are devastated. I mean, you've just been diagnosed with cancer. It's actually surprising because you could be diagnosed with a stroke or something like that and maybe definitely, the patient would be stressed. But maybe when you say cancer, even for patients that are doing great and will do great, the patients are terrified with a diagnosis of cancer.

– HAEMATOLOGIST, FRANCE

Many patients mentioned retrospectively what they wish could have happened with their diagnosis. What would have happened to their quality of life if they hadn't had a delayed diagnosis?



I wonder if my backbone could have been saved. I still do my work and I still do some sports not like running, but swimming. But it's all on a very low level, compared to what I did before. So, my life has changed dramatically due to the six months delay.

– MYELOMA PATIENT, BELGIUM



I wish it had been sooner so that after a month or two months and a complete analysis, they would have said look, it's a haematology problem, you have to go see a haematologist. Then surely my body would be different after a year or ten months, because of course, myeloma attacks, but it does it progressively.

– MYELOMA PATIENT, SPAIN

IMPACT OF A DELAYED DIAGNOSIS

THEME FOUR: IMPACT ON FAMILY MEMBERS AND CARERS

The survey with patients found that 45% of patients who experienced a delayed diagnosis and 40% of haematologists believed a delayed diagnosis had an impact on families' wellbeing. In addition to this, the focus groups revealed that many patients wanted open communication with friend and family members, however many struggled with the burden of being unwell on their family members. This was a theme predominantly raised by patients in the focus groups and interviews.



At some point I just had to tell them, you know, you have to leave. I can't stand this because I'm feeling so horrible in myself and seeing the grief in your eyes. I can see the pain in your eyes, how sorry and sad you feel about me being so ill. I cannot take it. It is very difficult to be in this position in your life but eventually you learn to live with it.

– MYELOMA PATIENT, DENMARK



First of all, the psychological impact when you know your significant one might die because of late diagnosis, because of sequelae's, because of handicap. It's a nightmare to with to live with this risk, with knowing that there might be something here that shorten your life. So, of course, for the family, it's extremely impactful psychologically.

– HAEMATOLOGIST, FRANCE



We know that the patient has very severe pain and bone lesions pain and of course, it's very stressful for the caregivers, and for all of the family members. So yes, it's bad for the patient and everybody around him.

– HAEMATOLOGIST, FRANCE

Furthermore, the focus groups highlighted patients often struggled with the sudden dependency on a loved one. The complications associated with a delayed diagnosis can mean that some patients no longer have the mobility to perform certain tasks and may cause additional financial burden to families if carers have to take time off working to support them.



There was no issue with regard to late starting of treatment and I accepted that and I have never had any issue or regret in that respect, that it wasn't recognized earlier. But I certainly, in terms of the wellbeing, my own personal wellbeing, the wellbeing of other members of my family, the diagnosis being earlier than the full year that it took, and many visits, would have made a difference to our wellbeing. I'm absolutely certain that it was a year of worry that we didn't really need to have.

– MYELOMA PATIENT, UNITED KINGDOM



I hear about patients who need to get up at 3 a.m. at night and they don't drive, and they need to bring someone with them and then they need to stay all day in the city. So I can understand that for some patients and for their carers it's a big change in life, because then someone else has to take a day off. They have regular treatments so they need to appear in the hospital, for example, every week, every one day of the month for some period of time. So, the carer is losing their holiday allowance or they are taking unpaid leave plus there's the cost of arriving in the city or staying the night.

– MYELOMA PATIENT, POLAND

IMPACT OF A DELAYED DIAGNOSIS

THEME FIVE: IMPACT ON CAREER AND FINANCES

Most patients in the focus groups believed that their delayed diagnosis did not have a direct impact on their finances, however 29% of patients who completed the survey did. Similarly, 26% of clinicians believed patient's finances would be impacted. Through discussions in the focus groups, patients did reveal they indirectly did lose money, whether related to having to take time off work, taking an early retirement or adaptations they have had to make for their symptoms and complications.

36% of patients revealed their delayed diagnosis had an impact on their career, which was echoed not only by clinicians in the interviews but also patients in the focus groups. Patients who have lasting symptoms and complications from their myeloma outlined that they were less able to work than before their diagnosis.



It was the second worst news of my life, the first, having the disease. The second was having to stop working. They forced me because I was a teacher... they forced me to retire and that made me feel terrible. I felt terrible that I had to stop working, and I had to fill it with something else.

– MYELOMA PATIENT, SPAIN



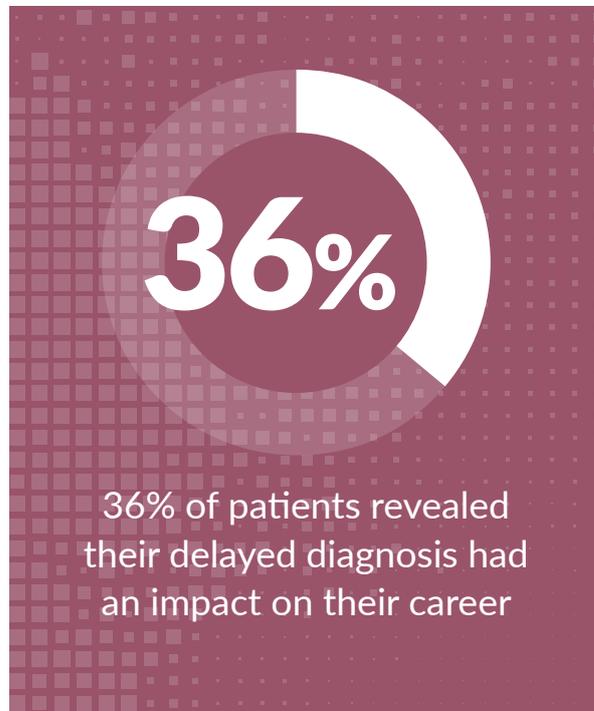
I recall thinking, does that mean I have to give up work? Does that mean that I will not be able to work? How will I be able to survive?

– MYELOMA PATIENT, UNITED KINGDOM



Disease has impact on every life aspect. Of course, it depends on how advanced the disease is, what symptoms the person is experiencing, but from my experience, I can say that it affected my emotional state, it affected my family's life. It affected my social life – people started to communicate with me less. Also, finances”

– MYELOMA PATIENT, LITHUANIA



And I guess that the more delayed a diagnosis is, that leads to effects on bones in terms of bone pain or bone fractures or anything like that, then that will clearly have an impact on how quickly the patient can recover and return to work. And clearly, returning to work is closely linked to patient's financial position.

– HAEMATOLOGIST, UNITED KINGDOM



Yes, you might have a financial impact essentially if you work, because you'll have to stop working at some point or you will repeatedly see the physician and on these days you will stop working. So you'll lose money. You won't make as much money as you used to. To that extent, delayed diagnosis might have a financial impact. Now, in France, myeloma is hundred percent covered by the Social Security system. So, the fact that you have myeloma will not have a financial impact because of the cost of the treatments. It has a financial impact because the money you make on a monthly basis will drop, but only if you work.

– HAEMATOLOGIST, FRANCE

IMPACT OF A DELAYED DIAGNOSIS

THEME SIX: TREATMENT OPTIONS AND SURVIVAL

As outlined above, late diagnosis impacts on symptoms and complications patients experience, quality of life and emotional wellbeing. In the survey patients and clinicians raised similar responses on the impact of late diagnosis on treatment options and survival. This was not really addressed by patients in the focus groups and interviews, however, haematologists interviews revealed that the progression of myeloma as a result of a delayed diagnosis would not have a direct impact on treatment options or overall survival, however the complications and comorbidities associated with a delayed diagnosis could have an impact on this. For example, having renal failure might impact on your ability to have certain drugs or having complications might prevent you from participating in a clinical trial.



It's a reasonable hypothesis, because you would think that if a patient has more advanced renal failure, then that can affect what drugs you can give them. That is, we know that poor renal function is associated with poor overall survival. In terms of bone fractures or anything like that, if that affects mobility and that affects patients' general well-being.

– HAEMATOLOGIST, UNITED KINGDOM



The main problem people have delayed diagnosis is if the patient has high risk, if the genetics are aggressive myeloma, that is difficult to be controlled with treatment. And only in this case the delayed diagnosis may create problems. Otherwise, I believe that if the patient has a standard risk myeloma, even after four or five months of delay, this would not affect the overall prognosis. Yes. The quality of life. Yes. But not the overall prognosis.

– HAEMATOLOGIST, GREECE



[A late diagnosis does] not necessarily [have an impact on a patient's treatment]. And I would say rarely the case. When you have a kidney issue it might because the kidney eliminates most of the drugs or the metabolites aren't metabolized and that could be an issue because we have to dose it up, we have to find the best schema to give the drugs to the patient optimally. And that could create a lot of issues and a lot of problems.

– HAEMATOLOGIST, FRANCE

Haematologists interviews revealed that the progression of myeloma as a result of a delayed diagnosis would not have a direct impact on treatment options or overall survival.

DIAGNOSTIC SOLUTIONS

TO GENERATE RECOMMENDATIONS AND ADVOCACY MESSAGES FOR TACKLING THE ISSUES RAISED IN THE SURVEY AND FOCUS GROUPS, WE ASKED PATIENTS AND HAEMATOLOGISTS ABOUT **POTENTIAL SOLUTIONS TO THE ISSUE OF DELAYED DIAGNOSIS**. THE THEMES ARE OUTLINED IN THE FOLLOWING SECTION, ALONGSIDE RECOMMENDATIONS FOR ACTION.



DIAGNOSTIC SOLUTIONS

THEME ONE: GP AWARENESS AND DIAGNOSIS AIDS

Focus group patients, and some clinicians, expressed the need for greater awareness among GPs as they are critical in the process of reducing diagnosis delays, and participants provided some examples of successful strategies they've seen for increasing awareness among GPs in their country. However, responders also recognised that as a rare disease, GPs may encounter only a few myeloma patients in their career. Therefore, the responsibility does not rely solely on GP awareness, but is one solution of many for improving timely diagnosis.



There is a gap and acknowledgement that the GPs should know more about the illness. We had a campaign for the GPs in Poland about two or three years ago, but I think a one campaign doesn't change much. It needs to be constant. Because even, in my case, to think that a doctor can say to you, "no clearly you don't have myeloma", is just so wrong because at least you should check and exclude on the scientific basis, not just what they think.

– MYELOMA PATIENT, POLAND



A year or two ago, we had made these postcards that said 'could it be MM' and gave it to them to hang on their wall or have on the desk. Just a postcard saying, 'could it be MM' for them to glance at this once in a while

– MYELOMA PATIENT, DENMARK



I think general noise is always needed...talking about diagnosis symptoms, talking about critical tests that are easy to be done. So just again, repeatedly, periodically refreshing the memory of physicians.

– HAEMATOLOGIST, CZECH REPUBLIC



This is something that the general practitioners are not really obliged to know, because malignant diseases usually go to tertiary health care, but they should be the first ones who think of these diseases. So education is always important.

– HAEMATOLOGIST, NORTH MACEDONIA

RECOMMENDATIONS:

- Educational programmes, awareness initiatives and decision-making aides for primary care should be developed to ensure doctors suspect myeloma and conduct the relevant tests and investigations, as appropriate.
- Development and use of myeloma referral guidelines. European and national referral guidelines for myeloma should be developed (where they don't already exist) and disseminated.
- Exploration of and development of predictive risk algorithms and prediction rules for primary care doctors. These can help estimate the risk of a patient having myeloma based on their clinical presentation and, where there is access to electronic health records, have the potential to be automated within software systems to flag-up patients at risk of having myeloma.

DIAGNOSTIC SOLUTIONS

THEME TWO: CONTINUOUS PROFESSIONAL DEVELOPMENT

The need for continuous education was mentioned by several clinicians. Given the rarity of myeloma, its ambiguous symptoms, and the lack or limited time spent in medical school learning about the disease, ongoing education can help increase awareness and potentially reduce diagnosis delays. This could come in the form of accredited continuing medical education, as is required in the US, or through conferences and other educational forums.



There is what we call a continuing medical education. This is mandatory in the US. It's starting to be implemented in France so that the doctors on a regular basis renew and update their knowledge. This is done by the French medical order, and then they organize that. It's not done yet, but it will soon come. But maybe the patient organization can make something.

– HAEMATOLOGIST, FRANCE



They have their own conferences and it's important to attend, let's say for three or four consecutive years. For example, I gave talks in the annual meetings of the Greek society for orthopaedic surgeons, talking about monoclonal gammopathies and increasing their awareness and then we'll have more patients diagnosed with MGUS, smouldering myeloma based on osteoporosis, for example. Once they hear you give some talks about these diseases and the symptoms, they don't forget that although it's not the most common, you have to have it in mind.

– HAEMATOLOGIST, GREECE



We make sure that for the future general practitioner, that we raise awareness, we tell them, we teach them about the bone issue, the kidney issue, to think about it, it could be myeloma. And that there is continuous education...we keep raising the alarm to be careful with these types of symptoms.

– HAEMATOLOGIST, FRANCE

RECOMMENDATION:

- Development of an online learning programme for GPs on myeloma and related conditions like AL amyloidosis and maybe other haematological cancers, potentially with continuous professional development points. This could be led by MPE in collaboration with professional societies.

DIAGNOSTIC SOLUTIONS

THEME THREE: GENERAL POPULATION AWARENESS OF LOOKING AFTER THEIR OWN HEALTH

The common symptoms of myeloma, including fatigue and bone pain, could be related to any number of health issues and, for the far majority of the population who experience these symptoms, they will not develop myeloma. However, patients and clinicians emphasised the importance of not ignoring symptoms and seeking medical attention when one's health changes.



I agree with him that it's not just a way of following the path the doctors stipulate for you. It's also informing yourself, reading about it and say what you. Because the rest of your life you will have to deal with it either way or another. The more you know about it, and the more you can come in a dialog with your doctors, it's easier to find your way to it.

– MYELOMA PATIENT, BELGIUM



But in actual fact, the driver to get it started, I believe, is down to the patient and you can't point the finger at anybody else. You've got to take responsibility for your own health. And certainly, there are no issues in the UK with regard to cost payments. It's completely free.

– MYELOMA PATIENT, UNITED KINGDOM



So permanent bone pain, any men and women should be aware that they should go and see their GP and that that would be the first thing.

– HAEMATOLOGIST, FRANCE



They may have been suffering with tiredness or lethargy and / or back pain these are the most common things that people say, oh, yes, but I actually had that symptom for a long time. But it might not be that they even felt that it was a severe enough symptom to seek medical help.

– HAEMATOLOGIST, UNITED KINGDOM



I think it's a lot of aspects. The general quality of health care system. The responsibility of patients who rarely go to the GP saying I have some trouble and problems. Some of our patients, thinking that it's normal and if it's normal, it's not necessary to be seen by a physician. It's unfortunate if we don't care properly about our health care, about our body.

– HAEMATOLOGIST, CZECH REPUBLIC

RECOMMENDATION:

- Government funded public health campaigns which promote GP attendance if health changes or general symptom awareness of the signs of cancer.

DIAGNOSTIC SOLUTIONS

THEME FOUR: RAISING AWARENESS AMONGST “OTHER” SPECIALISTS

Beyond GP awareness, patients and clinicians discussed raising greater awareness among specialists. So as to target awareness efforts, greater emphasis could be placed on specialists more likely to encounter myeloma patients as a result of renal or orthopaedic symptoms.



If patients have something they are suffering from and many times it's sad to hear about the long period of time they have been struggling with their pain until they are diagnosed. Until the right doctor does the right diagnosis and says, okay, this is suspected multiple myeloma. I think it should start with the orthopaedic doctor, because myeloma often comes from a pain in the bones.

– MYELOMA PATIENT, ISRAEL



I would want the focus not to necessarily always be on GPs, but on the hospital specialists and other hospital doctors to try and pick up. That you know, first presentation to any hospital or specialty to diagnosis. And then the second thing is around kind of tests, access to testing, so making sure that anybody who sees a patient can access all the right tests that they need if it is something that they suspect or think about and have access to kind of early pathways into haematology.

– HAEMATOLOGIST, UNITED KINGDOM

RECOMMENDATIONS:

- Expand a diagnosis pathway campaign to other healthcare specialists.
- Hospital specific cross-speciality training to remind people about the signs, symptoms, and complications of different diseases.

DIAGNOSTIC SOLUTIONS

THEME FIVE: COMMUNICATION BETWEEN PRIMARY AND SECONDARY CARE

Improved communication between primary and secondary clinicians was discussed as an important step that would help raise awareness of myeloma, reduce diagnosis delays, and potentially improve patient outcomes through information sharing. Given the number of clinicians myeloma patients see during their path to diagnosis, and throughout the treatment, better communication is essential for patient-centred care.



One thing is that doctors should talk to each other much more. So that it's one important thing because sometimes you just get a prescription that you should go to another doctor and then information is missing. Either there's no letter from the doctor or there's misunderstanding. So this is one thing where it could be accelerated. Another thing is also to make more awareness about the disease, what that disease is and that early treatment, of course, helps to survive longer.

– MYELOMA PATIENT, GERMANY



Yes. I think the communication between medical specialists, haematologists and the general practitioners is very important. When the medical specialist writes letters to the GP about the development of the illness of the patient, the GP is much more informed about what to be assessed.

– MYELOMA PATIENT, THE NETHERLANDS



Only one probably proper measurement is to give the GP feedback. If I received a patient with significant delay and troubles, I immediately called the GP saying, okay this patient was in your outpatient clinic one year ago and had pain and the pain was quite significant. So please, the next time just send the patient to just simply get an X-ray, check the protein level. This is I think a good approach.... maybe the next time just he will do something different.

– HAEMATOLOGIST, CZECH REPUBLIC

RECOMMENDATION:

- Haematologists to consider providing feedback during “teachable moments” such as where patients have experienced significant delays in diagnosis that could have been avoided. Hospitals should also consider significant event audits where patients who have experienced big delays are reviewed for improvements and learnings.

DIAGNOSTIC SOLUTIONS

THEME SIX: POTENTIAL OF SCREENING

Some patients suggested broader screening programs to detect myeloma and other diseases early; however, clinicians were more hesitant to suggest this and mentioned that more data is needed before making a decision on screening. They also pointed out that the burden on the healthcare system and general population might be too high for the rarity of myeloma. Further exploration is needed to understand the benefits of screening and practicalities of implementation.



I think that there should be mandatory blood tests, that are done annually in order to prevent not only blood cancer but also other diseases. And it should be more detailed test, not the same that every person can get from GP once a year. I know that the cost of testing would not be small, but I think it could prevent many diseases, it could warn about changes in the body even when symptoms are not specific. Of course, if a government would assign more money to the healthcare – for tests, scanning, etc., maybe people would get better care and faster diagnosis as well.

– MYELOMA PATIENT, LITHUANIA



If these GPs could have a procedure or some schema to run through. They do it for mammography, for breast cancer, you get a regular check-up for intestine cancers and so on, several other diseases. They try to prevent the breakout just by looking for them at a certain age. And like you said, it's an easy blood test and urine test. They could easily do it from 50 years old. Of course, you can't screen the whole population, but we see that the majority is 50 plus. And for some exceptions.

– MYELOMA PATIENT, BELGIUM



For me, the evidence isn't there yet. So there are a couple of ongoing big screening studies, so iStopMM and PROMMISE, that will hopefully provide information to us around whether those are the right approaches, the right ways to go. For me it's too early to start thinking about screening the general population. I think you just end up causing a lot of anxiety without knowing what you're going to do about it.

– HAEMATOLOGIST, UNITED KINGDOM



They are rare diseases, and you have to show that the specific test is cost effective also. Greece is a small country, we have 11 million but if I'm going to test all people above the age of 50, that is half the population because we are an elderly country. And then you have to check all of these people once per year with electrophoresis in order to capture, let's say, 3%, 2% of them with MGUS and then to follow up with them until they have myeloma. And this is 1.5% per year. I don't know how cost effective this is, but it will be good to know from the Icelandic study.

– HAEMATOLOGIST, GREECE

One clinician mentioned that screening wasn't done in myeloma, but through a cooperation with their Department of Biochemistry, certain results triggered a need for a specialist, which acted as a type of screening.



What we are doing, and I think it's a very easy measurement which can be done across the world, is a cooperation with the Department of Biochemistry. Whenever some critical value of a protein or immunoglobulin are high, they check this patient and announce that the patient should be evaluated in an outpatient clinic. And it's working nicely. So it's not screening, but it's facilitated screening and it's working.

– HAEMATOLOGIST, CZECH REPUBLIC

DIAGNOSTIC SOLUTIONS

RECOMMENDATIONS:

- Begin a discussion on screening approaches. Explore potential strategies, or targeted screening approaches, so patients are picked up before getting seriously unwell.
- Whilst we know that screening may overburden healthcare systems, there could potentially be exploratory studies of the viability of screening tests in myeloma or how the community better monitors MGUS and identifies high-risk patients before it progresses to myeloma.

“
Further exploration is needed to understand the benefits of screening and practicalities of implementation.
”

DIAGNOSTIC SOLUTIONS

THEME SEVEN: POLICY INITIATIVES FOCUSED ON IMPROVING DIAGNOSIS OF RARE CANCERS, INCLUDING ACCESS TO DIAGNOSTIC TESTS IN PRIMARY AND SECONDARY CARE

National and EU healthcare policies must reflect the importance of early diagnosis and actions that focus on improving access to diagnostic tests, especially as the availability and costs vary across European countries. Collective advocacy efforts aimed at policy makers and government officials can help shed light on the broader impacts of early diagnosis, not just on the patient, but on the healthcare system and society.



I think what is also important is to make aware the policymakers that it's important to have an early diagnosis because it affects not only the patient, but also the society. Right. Because if someone is diagnosed earlier, they can still work and they can bring income.

– MYELOMA PATIENT, POLAND



We have two labs that can perform genetic analysis on a molecular basis, and we tend to do the analysis in every patient, but I'm still not very confident with that. One reason for not performing the genetic analysis is that part of the expenses would go to the patient, and the other reason is that we only have one line of treatment for these patients. So there is no point of making genetic analysis if you can only apply one treatment. It's one option for all patients, regardless of their genetics. So these are the two main issues that patient organizations can push for: the availability of modern diagnostic tools and the availability of modern drugs.

– HAEMATOLOGIST, NORTHERN MACEDONIA



So free access to serum protein and urine protein electrophoresis. And you would cover most of the myeloma diagnosis.

– HAEMATOLOGIST, FRANCE

RECOMMENDATIONS:

- Variations in diagnosis times and access to diagnosis tests should be monitored by national registries and health systems, and through initiatives in Europe's Beating Cancer Plan, such as the via the Inequalities Register. Only by understanding the situation can we develop solutions.
- Integration of diagnosis strategies for rare and difficult to diagnose cancers into cancer plans. Comprehensive strategies to improve the diagnosis of myeloma, and other rare and difficult to diagnose cancers, should feature strongly in European and national cancer plans. This should include sharing best practice and piloting initiatives to understand what is likely to have the biggest impact on improving diagnosis.

LIMITATIONS

THIS RESEARCH HAS POTENTIAL LIMITATIONS THAT SHOULD BE CONSIDERED.

SURVEY LIMITATIONS:

First, hundreds of more patients completed the survey compared to physicians and therefore we cannot accurately compare perceptions on diagnosis between these two groups. Furthermore, the research project was designed to gather general European perspectives and the representation across countries was variable (see appendix 5), therefore cross-country analyses were not done. This also means that some results may have been skewed to high response rates from certain countries.

FOCUS GROUP LIMITATIONS:

It is important to emphasise that focus group and interview participants were from similar demographics and therefore certain county-specific socioeconomic issues may not have been raised. MPE also acknowledges the lack of representation from Central and Eastern European countries may have skewed certain discussions surrounding access issues. Furthermore, participants may have had limited knowledge on certain topics, such as, access to tests available in primary care, limiting some of the discussions. Lastly, the mean age of focus group attendees was 58, which is lower than the average age for myeloma patients. Therefore, some of the experiences of a delayed diagnosis may not be representative of an older patient's experience.

CONCLUSION

Diagnosing a rare disease with nonspecific symptoms is challenging and caused by a multitude of factors. Disparities in access to testing, availability of GP appointments, overburdened and under-resourced healthcare systems, and several other issues can result in a patient waiting months to receive a diagnosis.

A delayed diagnosis can impact treatment options and response, mental and emotional health, physical fitness, and extend beyond the patient to affect family members and financial stability, whilst a timely diagnosis can improve a patients' outcomes and quality of life.

A complex problem requires a multi-pronged solution, with efforts undertaken by all relevant stakeholders. In the recommendations section MPE has outlined several strategies that can be advocated for and implemented on the individual, health care system, and policy levels. With the support of patients, carers, advocates, health care professionals, health systems administrators, policy makers, government officials, industry, academia, and medical societies, we can enact measures to help reduce delays in diagnosis and improve patients' quality and length of life.

ACKNOWLEDGEMENTS

MPE would like to extend a special thank you to the patients and clinicians who took part in this study, we are grateful for your time and generosity in sharing your experiences. MPE also appreciates the efforts of our member organisations who supported the project with patient recruitment and dissemination, thank you for making this research possible.

APPENDICES

Appendix 1: [Survey on myeloma and AL amyloidosis diagnosis.](#)

Appendix 2: [Myeloma Patient Focus Group – Discussion Guide.](#)

Appendix 3: [Interview guide clinicians – Myeloma and AL amyloidosis.](#)

Appendix 4: [Myeloma Patients Early Diagnosis Pre-reads.](#)

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