Over one-third of European myeloma patients experience delays in diagnosis. 'Myeloma Diagnosis Across Europe', a pan-European survey and focus groups report published on European Myeloma Day (September 27th), revealed a landscape where diagnosis of myeloma can take over five months, require more than four medical consultations and involve visits to at least three different medical specialists. The survey, by Myeloma Patients Europe (MPE), found that 11% of patients had been diagnosed in hospital emergency departments.

"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," write the authors of the report.

Each year in Europe around 50,000 people are diagnosed with myeloma, a cancer of plasma cells. Excessive plasma cells may eventually mass together to form tumours in various sites of the body, especially bone marrow. Despite being the third most common type of blood cancer, myeloma is especially difficult to diagnose, because symptoms – such as pain, easily broken bones, fatigue, and recurring infections – are often linked to general ageing or minor conditions. Myeloma Patients Europe (MPE), an umbrella organisation of myeloma and AL amyloidosis patient groups across Europe, decided to undertake the survey to understand directly from myeloma patients and haematologists about their experience of diagnosis.

In the study MPE used a mixed-methods research methodology, starting with a European survey and followed by patient and haematologist focus groups and interviews. In total, 628 myeloma patients across 28 European countries and 80 haematologists across 16 European countries completed the survey, and 23 patients and six haematologists took part in focus groups and interviews.

Results showed:

- **Time to diagnosis**. Approximately 51% of patients waited three or more months after the onset of symptoms before seeking medical help. First presentation of symptoms or abnormal blood results occurred at the GP practice in 63% of cases and in the emergency hospital department in 11% of cases. Approximately 24% of patients said that they waited five or more months to get a diagnosis, contrasting with 13% of haematologists who stated that it took their patients five months or more to get a diagnosis.
- **Number of consultations**. Most patients reported that they saw up to three different specialists (e.g. primary care, renal and orthopaedic) before receiving a diagnosis, while 21% saw more than three. This contrasted with only 14% of haematologists stating their patients saw more than three specialists. 45% of patients had more than three medical consultations and 22% more than six.
- **Delays in diagnosis**. Approximately 34% of patients stated their diagnosis was delayed, in contrast to 25% of clinicians who described the timing of diagnosis in their country as delayed.

"One of the main barriers to diagnosing myeloma is that patients can have non-specific symptoms. The main symptoms, such as back pain or fatigue, are common and myeloma is a rare disease. Most GPs will only see a few cases of myeloma in their career, making it very difficult for them to suspect it," says Charlotte Pawlyn, a haematology consultant at the Royal Marsden Hospital , London, and a member of the MPE Medical Advisory Committee.

Based on the survey results and focus group discussions, MPE developed the following recommendations:

- **Awareness initiatives and decision-making aids for GPs** should be developed, to ensure they can recognise symptoms that may be suspicious for myeloma and conduct relevant tests and investigations. MPE has developed a Myeloma Diagnosis Pathway outlining the main signs and symptoms and tests that should be undertaken when myeloma is suspected.

- European and national reference guidelines for myeloma should be developed (where they do not already exist) and disseminated.
- **Predictive risk algorithms** should be developed to estimate the risk of a patient having myeloma.
- **On-line learning programmes** on myeloma should be developed for GPs, with points for continuous professional development.
- Governments should fund public health campaigns aimed at **prompting people to visit their GP** if they experience health changes and raising awareness of general symptom and signs of cancer.
- Haematologists should consider providing **feedback on 'teachable moments'**, where patients have experienced significant delays that could have been avoided.
- Exploratory studies should be done on **viability of screening tests** and how the community could better monitor monoclonal gammopathy of underdetermined significance (MGUS) – a non-cancerous precursor condition of myeloma.
- Comprehensive strategies to improve diagnosis of myeloma and other rare and difficult to diagnose cancers should be integrated into **European and national cancer plans**.