PUMMaCE
Patient Understanding of Multiple Myeloma and Communication Experiences

SHORE-C
Sussex Health Outcomes Research & Education in Cancer

Patient Understanding of Multiple Myeloma and Communication Experiences (PUMMaCE): Survey Summary

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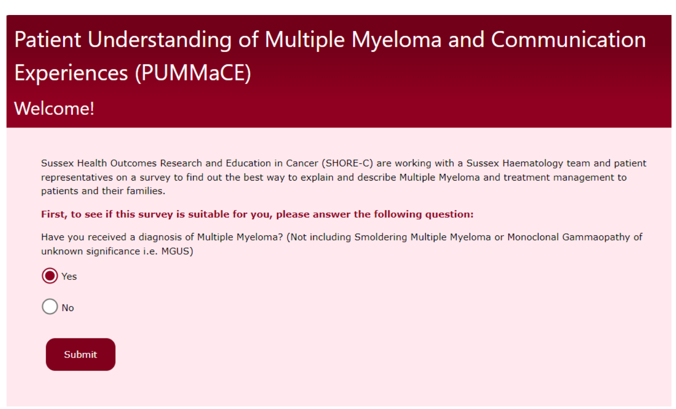
Background: Multiple myeloma is a complex haematological malignancy with advanced medical terminology and a variety of treatment options which can be overwhelming for both patients and caregivers. We developed a UK wide online survey to explore the communication experiences of those living with myeloma and their understanding of the condition.

The online survey comprised 6 sections:-

1) Demographics
2) Terms used to explain multiple myeloma
3) Communication of the diagnosis
4) Communication around treatments and support
5) Family/friends' understanding of multiple myeloma (MM)
6 a) Things family/friends said/did that were helpful or not so helpful
6 b) Things doctors/nurses said that helped or hindered understanding of diagnosis
6 c) Things doctors/nurses said that helped or were not so helpful



Patient Understanding of Multiple Myeloma and Communication Experiences (PUMMaCE)
Welcome!

Sussex Health Outcomes Research and Education in Cancer (SHORE-C) are working with a Sussex Haematology team and patient representatives on a survey to find out the best way to explain and describe Multiple Myeloma and treatment management to patients and their families.

First, to see if this survey is suitable for you, please answer the following question:

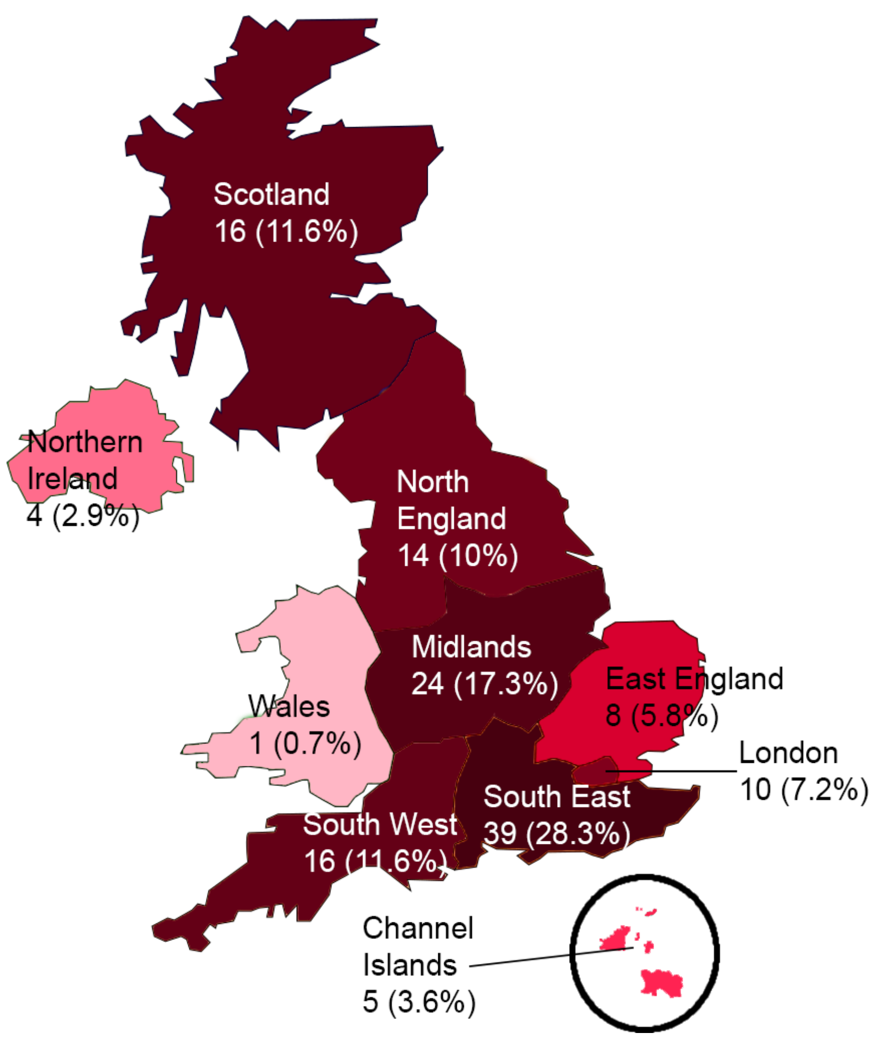
Have you received a diagnosis of Multiple Myeloma? (Not including Smoldering Multiple Myeloma or Monoclonal Gammaopathy of unknown significance i.e. MGUS)

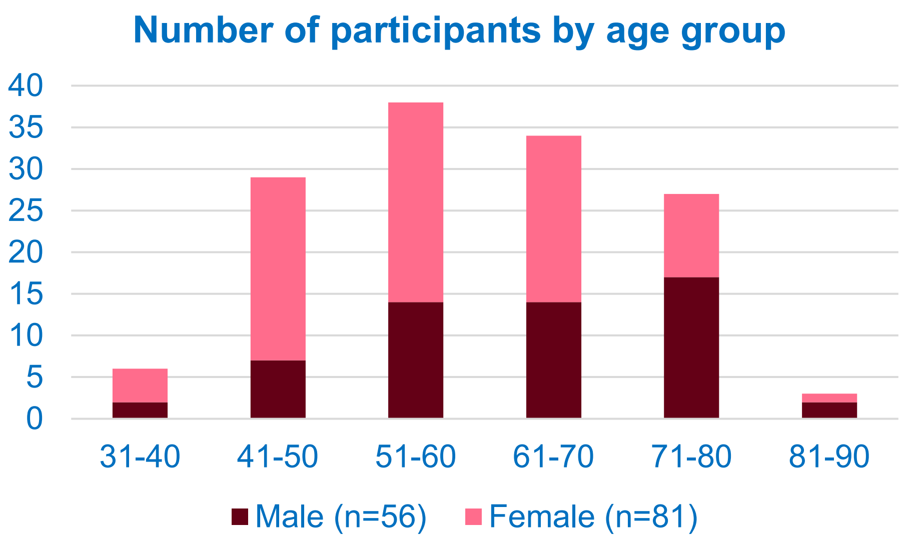
● Yes
○ No

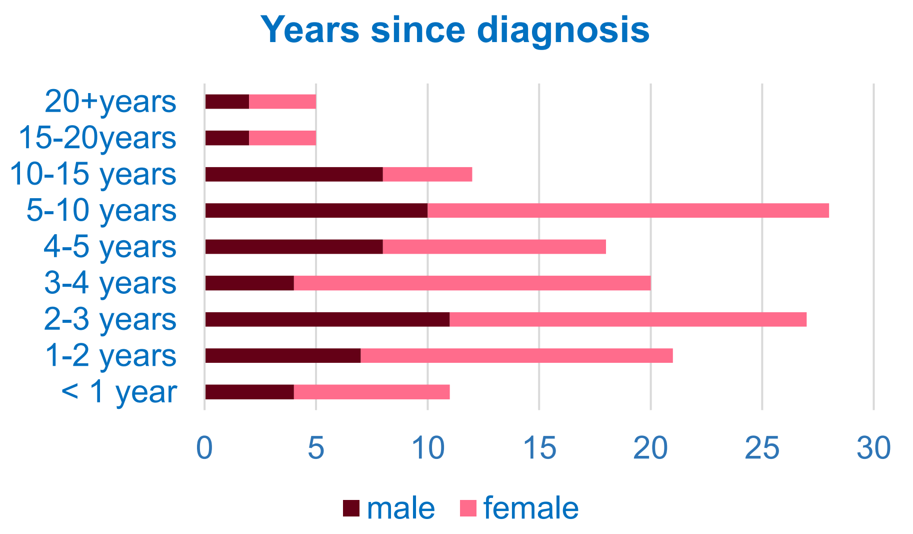
The survey was live for 3 months Jan-Apr 2025
PUMMaCE was approved by the BSMS Research and Governance Ethical Committee (Ref: ERVAL/1)

Key Findings

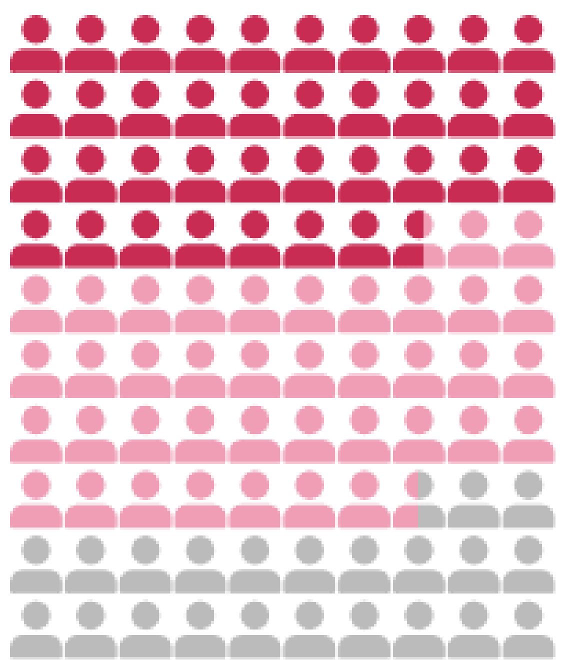
1) **Demographics**: 138/151 (91%) people completed the survey; **75%** had not heard of Multiple Myeloma before their diagnosis.




Number of participants by age group


Years since diagnosis

Symptoms before diagnosis



dark pink = 3 or more (37%)

light pink = 1 or 2 (40%)

grey = no symptoms (22%)

Most frequent symptoms

bone pain (46%)

tiredness (44%)

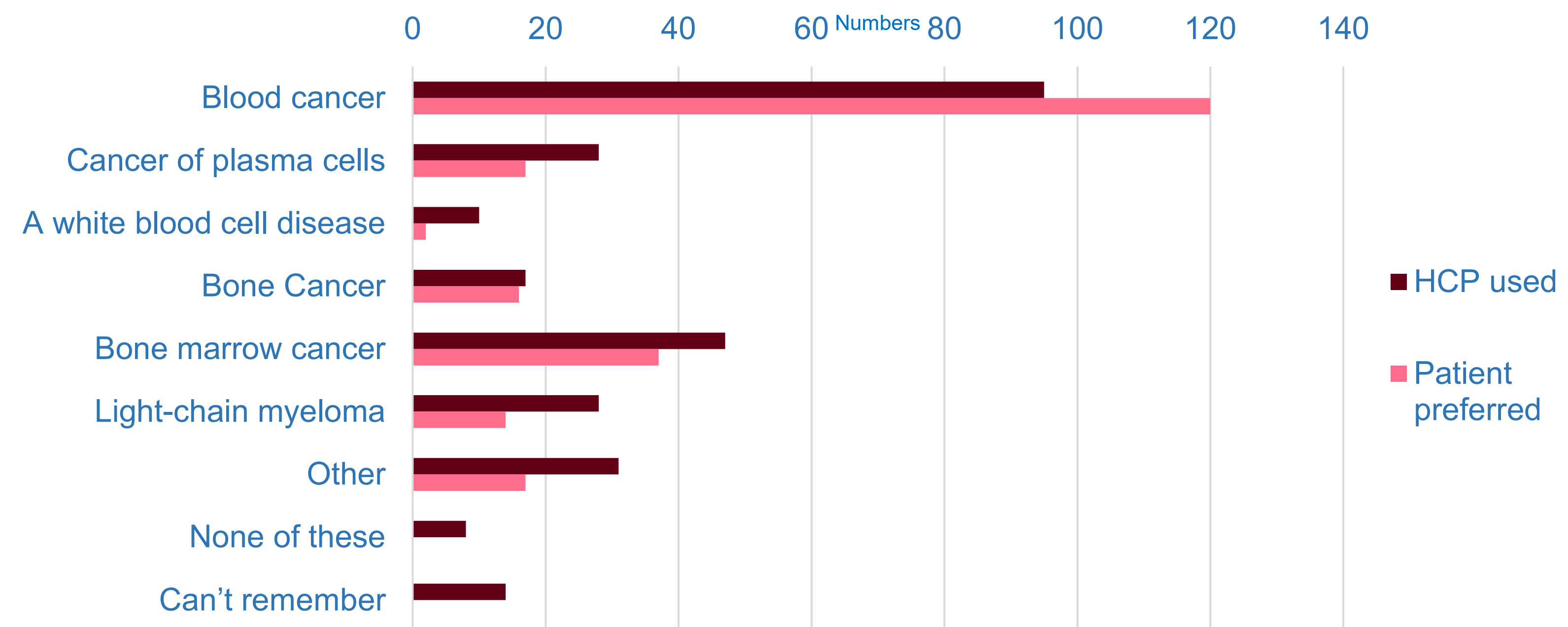
GP

71% first saw GP with symptoms

10% saw GP ten + times before referral to haematology

40% received diagnosis within 3 months

2) **Terms to describe multiple myeloma:** graph shows the phrase the patient said the health professional used and patients' preference.



3) Communicating the diagnosis:
The haematologist usually gave the diagnosis (70%), but occasionally it was the GP (10%).
It was given mainly in person (87%) but only 56% had a family member/friend present at the time.
80% of people had access to a haematology nurse specialist.

4) Treatments & support
85% of respondents stated their satisfaction with the communication and information they received about treatments. 93% believed the aim of treatment was to control the myeloma and prolong their life.

2/3rds of respondents said they wanted to know their **prognosis,** but it was only discussed with 56 people, and this was because they had asked 42/56 (75%).

5) Family & Friends' understanding of MM
Respondents said they thought their friends and family understood their illness (99/138; 72%), but a quarter thought they did not understand or were unsure.

Just over half reported that they had discussed their diagnosis & prognosis with them (54%), however 58% said that their HCP had not discussed anything with their family.

Examples of positive and negative free text quotes

We received hundreds of free text comments which we are analysing in more detail. Below are a few quotes from three of the areas.

Things family/friends said or did that helped or were not so helpful

Positivity regarding prognosis, as nobody knows

Visited

Doomsters

Hugs

Those how awful / well-meaning but downbeat voices.

Cleaned

Cooked food when unable

Transported to hospital

Laughed together

Things health care professionals said or did that helped or were not so helpful

Responding to emails and phone calls

Listening

Saying "myeloma is the good cancer, if I was going to choose one it's what I would choose as there are lots of treatment options". It downplays what you are going through

Being easy to contact

Things health care professionals said that helped or hindered your understanding of a MM diagnosis

Explaining the disease in simple terms and drawing diagrams

Using multiple terms for things such as autograft for autologous stem cell transplant and plasma cell neoplasm for cancer cells is confusing

Being clear and honest

Next steps
Submit a manuscript of the findings for publication
Obtain grant funding to:-
a) produce easily accessible short films to help improve patients' & families' knowledge and understanding of MM.
b) develop communication courses for of healthcare professionals working in haematology.

Many Thanks to all who took part in the survey