

# The Big Wm Survey



The Big WM Survey took place in August 2024. It was carried out through Survey Monkey, and comprised of two different surveys: one for WM/LPL patients and one for family members, friends and unpaid carers of people living with WM/LPL.

## Who completed the survey?

- 372 valid\* responses to both surveys
- 92% from the British Isles
- 85% WM/LPL patients
- 15% were family members, friends or unpaid carers of people living with WM/LPL (loved ones)



**59%**  
patients were female



**41%**  
patients were male

\*responses were only counted if the required fields were completed and respondents were from the British Isles or Europe

## Mental health

- The majority reported at least one negative mental health impact since their diagnosis
- 37% of patients felt anxious about the future, compared to 50% of loved ones
- 42% of patients on Active Monitoring reported high levels of anxiety around check-ups and test results
- Patients reported a wide variety of changes to their lifestyle due to their diagnosis, whilst 34% of loved ones had reduced their social activities
- 37% of loved ones felt the need to stay positive, despite not feeling that way
- Loved ones were also less likely to report positive mental health impacts from the diagnosis than patients. 25% of patients reported at least one positive mental health impact since diagnosis
- 37% of patients worried about their loved ones, compared to 50% of loved ones who worries about the person they support

## Lack of information

- 73% of patients wanted to 'know everything' about WM/LPL when diagnosed
- 26% of patients received no take-home information whatsoever when diagnosed, whilst a further 40% only received general blood cancer information
- 69% of patients were told they had WM, with the remainder being told more general terms
- 5% of patients were not even told they had blood cancer
- 38% of patients have not discussed lifestyle management with their HCP, including things such as protecting against infections and vaccinations
- 27% of patients and 31% of loved ones understood the information given at diagnosis
- 23% of loved ones felt that the person diagnosed couldn't clearly explain their diagnosis
- 77% of patients are relying on online searches to find out more about their disease

## Route to diagnosis

- 2/3 of patients visited their GP three or more times before being referred for further tests
- The more symptoms someone presented to their GP with, the more likely they would need to visit their GP multiple times
- The majority of those who only visited their GP once, presented with only one symptom
- 20% of patients waited over a year for their diagnosis from first visiting their GP