# Improving the quality of active monitoring in Waldenström macroglobulinemia: Results of a UK-wide patient-centered experience survey and proposed standard of care for active monitoring from a UK-wide patient-expert collaboration

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## ABSTRACT

**Introduction:** Patients with Waldenström macroglobulinemia (WM) are often asymptomatic at the point of diagnosis and may remain so for several years. Regular monitoring for clinical changes, known as watch and wait, active surveillance, or active monitoring (AM), is essential. In the UK there are no data on the consistency or quality of patient experience of AM and no standardized approach to the definition and components of AM.

**Methods:** To understand the views of patients and healthcare professionals (HCPs) on their AM experience, a steering group was convened. The group included people living with WM and HCPs who manage WM, including consultant hematologists and clinical nurse specialists. A patient survey was created to determine the quality and consistency of AM for people living with WM in the UK. This was designed by WMUK, a UK charity and patient organization supporting people living with WM. Members of WMUK completed the survey via email. To define a standard of care for AM, a survey of 40 Likert-scale statements across 6 clinical domains was created and distributed online to HCPs and people living with WM. The survey responses were used to inform and create a consensus on recommendations on a new standard of care for AM in WM and a checklist to support and inform the patient-HCP discussion during consultations.

**Results:** *Patient experience of AM:* 168 survey responses were analyzed. Age of respondents was recorded in 10-year cohorts from 35 years to 75+ years; most (34%) respondents were in the 66-74 age range. 150 (89%) respondents lived in England, 11 (7%) in Scotland, 3 (2%) in Wales, and 4 (2%) in Northern Ireland. 108 (78%) respondents had been on AM for >2 years at the time of the survey. Thirty-two (22%) did not receive an explanation of AM at diagnosis, and 116 (69%) did not receive any written information about AM; 108 (64%) respondents stated that they were not directed to support services while on active monitoring. 83 (51%) respondents stated they were not given information on symptoms of disease progression for self-monitoring. 105 (63%) respondents stated their experience of AM could have been improved. *HCP/patient consensus on standards in AM:* 232 responses were analyzed (189 [81%] people living with WM and 43 [19%] HCPs), with 39/40 statements attaining very strong (≥90%) agreement. No statements failed to meet the agreement threshold (75%). From these, 7 recommendations were created defining AM and minimum clinical standards of AM, outlining the role and composition of the multidisciplinary team, and identifying the need for access to educational materials and support from patient organizations. A patient checklist of areas to cover during consultation was also generated.

**Conclusions:** This study demonstrates that the patient experience of AM across the UK is highly variable, with more than half of participants stating their experience could be improved. The ensuing consensus statement provides a strong foundation for best clinical practice and a template for the communication of information during the AM phase of WM.