Proposed Standard of Care for Active Monitoring in Waldenström Macroglobulinemia From a UK-Wide Patient-Expert Collaboration

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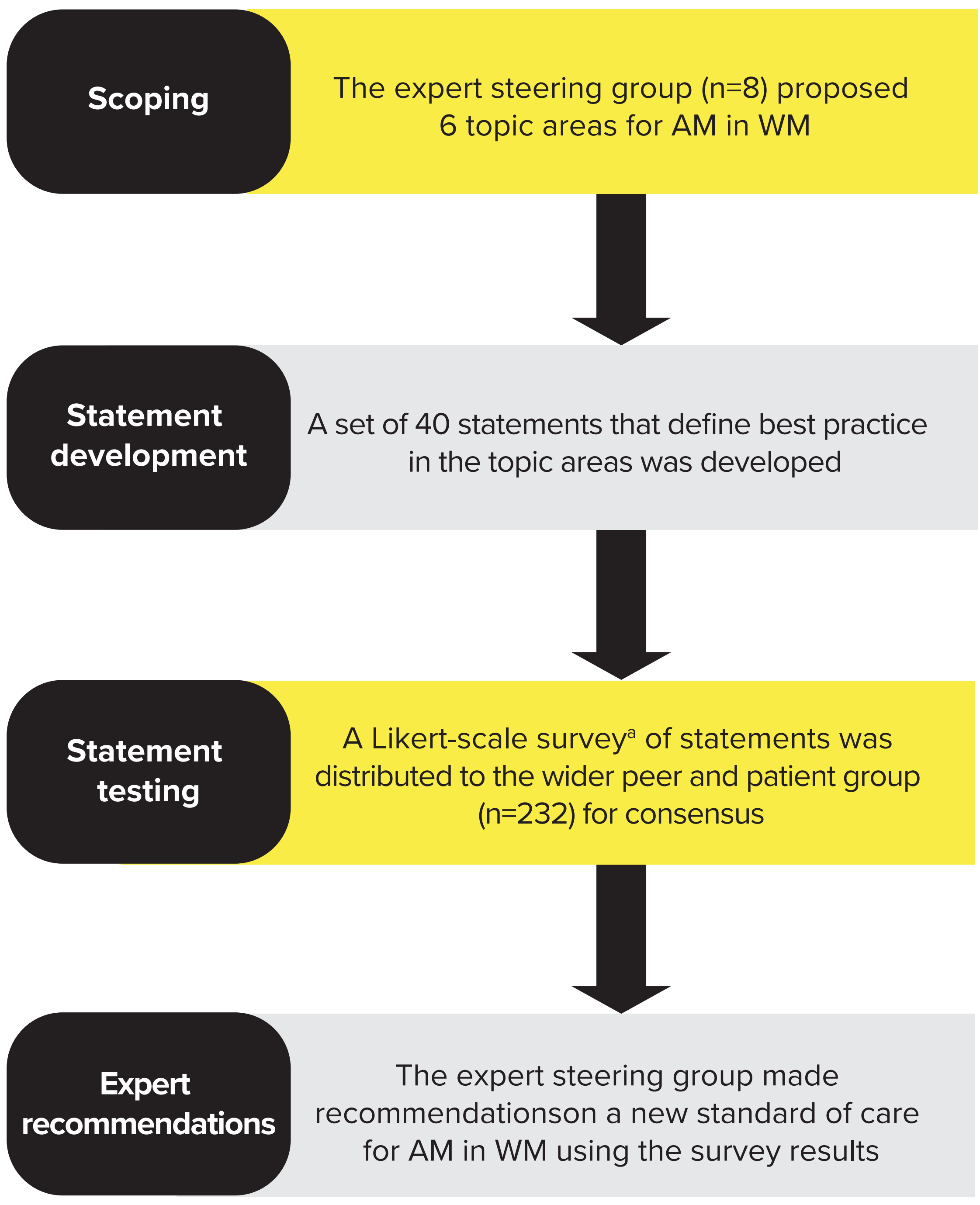
INTRODUCTION

- Patients with Waldenström macroglobulinemia (WM) are often asymptomatic at diagnosis and may remain asymptomatic for several years[1]
- Patients are reviewed by their specialist team every 3-6 months to monitor for changes or additional symptoms related to WM[1]
- The time between diagnosis and treatment initiation is referred to as watch and wait, active surveillance, or active monitoring (AM)[1]
- As there is no evidence that immediate treatment is beneficial, AM ensures that treatment is started when necessary, avoiding treatment side effects and maintaining patients' quality of life[2]
- 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[2]
- Here, the views of patients with WM and healthcare practitioners (HCPs) on their AM experience were used to create a consensus on recommendations for a new standard of care for AM in WM

METHODS

- An anonymous 20-question survey was created and disseminated to patients with WM across the UK to determine the quality and consistency of AM
  - This was designed by WMUK, a UK charity and patient organization supporting people living with WM
- A modified Delphi approach was used to establish a consensus on recommendations to improve the experience of patients and HCPs (**Figure 1**)
  - The study was led by a steering group of 8 experts in WM management and patient support from across the UK
  - A group of 189 patients with WM and 49 HCPs who manage WM took part in the survey

Figure 1. Consensus Methodology



Scoping — The expert steering group (n=8) proposed 6 topic areas for AM in WM

Statement development — A set of 40 statements that define best practice in the topic areas was developed

Statement testing — A Likert-scale survey[a] of statements was distributed to the wider peer and patient group (n=232) for consensus

Expert recommendations — The expert steering group made recommendationson a new standard of care for AM in WM using the survey results

Consensus was set at 75% agreement, and ≥90% agreement was considered very strong agreement

[a]Response options were strongly agree, tend to agree, tend to disagree, and strongly disagree.
AM, active monitoring; WM, Waldenström macroglobulinemia.

RESULTS

Patient Experience of AM

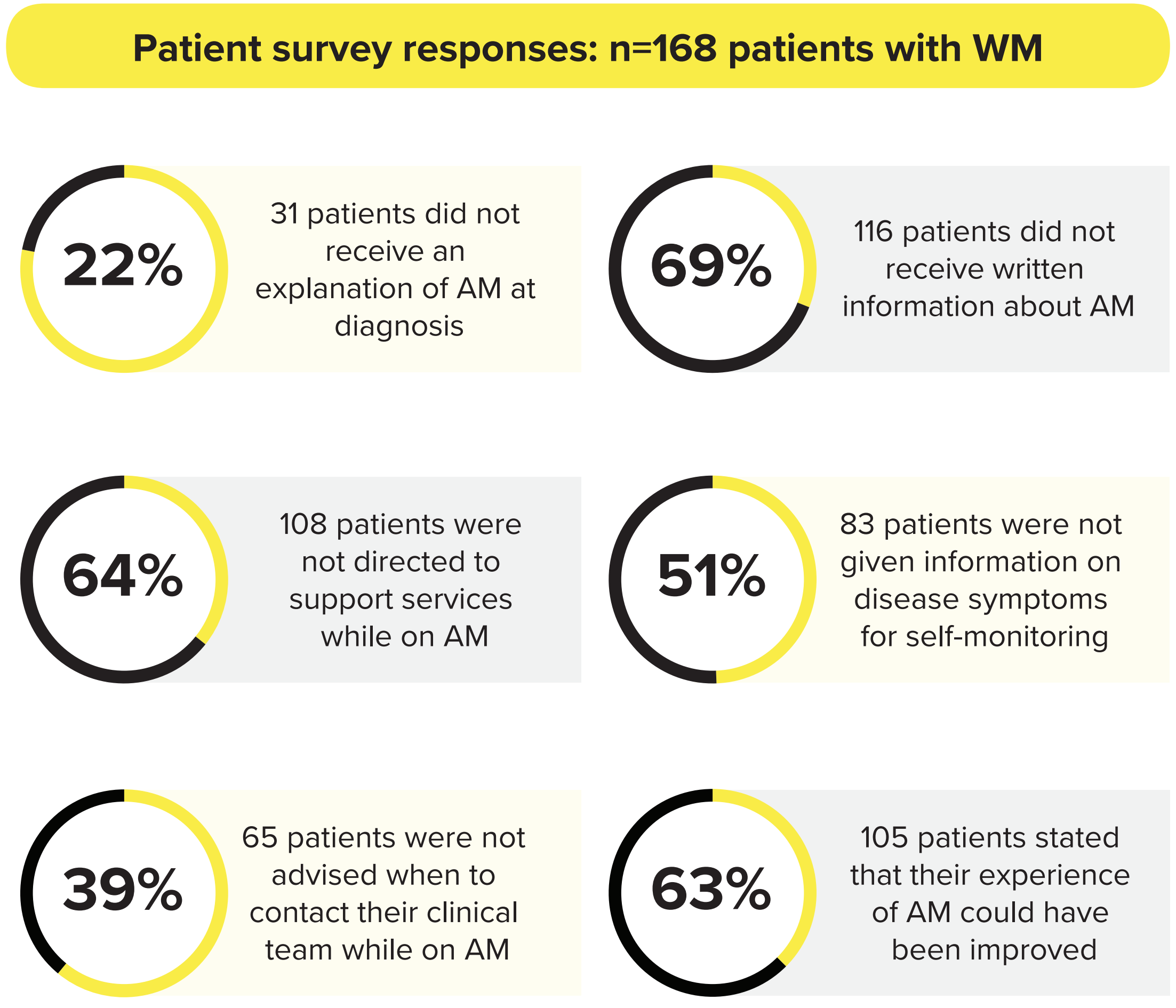
- As of May 20, 2024, 168 patients with WM had responded to the patient survey
- The majority of respondents were on AM at the time of responding (89%) and had been on AM for >24 months (78%) (**Table 1**)
- Responses to the patient survey are summarized in **Figure 2**

Table 1. Baseline Demographics of Patients With WM Who Responded to the Patient Survey

Characteristics, n (%)	Patients (n=168)
Sex	
Female	97 (58)
Male	71 (42)
Age categories	
≥75 years	53 (32)
65-74 years	62 (37)
55-64 years	44 (26)
45-54 years	7 (4)
35-44 years	2 (1)
Region	
England	150 (89)
Scotland	11 (7)
Northern Ireland	4 (2)
Wales	3 (2)
Currently on AM	
Yes	149 (89)
No	19 (11)
AM duration	
>24 months	116 (78)
12-24 months	17 (11)
6-12 months	10 (7)
<6 months	6 (4)
Treatment prior to AM	
Yes	92 (55)
No	76 (45)

AM, active monitoring; WM, Waldenström macroglobulinemia.

Figure 2. Patient Survey Responses



Patient survey responses: n=168 patients with WM

22% — 31 patients did not receive an explanation of AM at diagnosis

69% — 116 patients did not receive written information about AM

64% — 108 patients were not directed to support services while on AM

51% — 83 patients were not given information on disease symptoms for self-monitoring

39% — 65 patients were not advised when to contact their clinical team while on AM

63% — 105 patients stated that their experience of AM could have been improved

AM, active monitoring; WM, Waldenström macroglobulinemia.

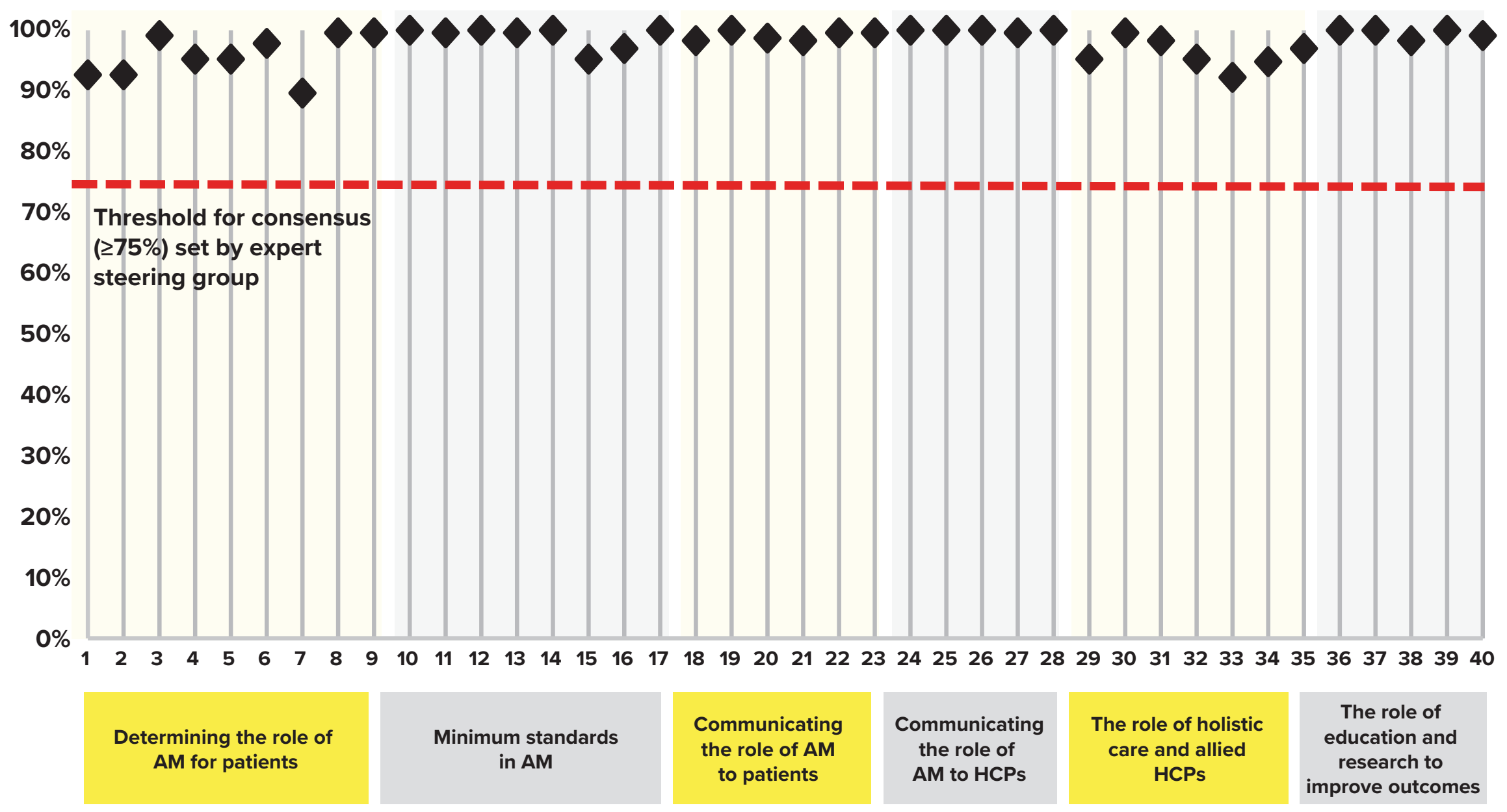
HCP and Patient Consensus on Standards in AM

- A total of 232 responses were analyzed, including 189 people living with WM (81%) and 43 HCPs (19%)
- No statements failed to meet the agreement threshold (75%), and 39 of 40 statements attained very strong agreement (≥90%) (**Figure 3**)

CONCLUSIONS

- This study demonstrated that the patient experience of AM across the UK is highly variable in terms of quality and content
- More than half of participants stated that their experience of AM could be improved
- The consensus statements and patient consultation checklist developed provide a strong foundation for best clinical practice and a template for the communication of information during the AM phase of WM

Figure 3. Consensus Results by Topic and Statement



AM, active monitoring; HCP, healthcare practitioner.

Figure 4. Recommendations to Improve the Experience of AM

1. **The term *active monitoring* is preferred** for the period between diagnosis and initiation of active treatment. This term is used in patient groups, and adoption by HCPs would improve consistency in the language used
2. **A choice of virtual and face-to-face appointments should be offered to patients** if they experience any new signs or symptoms
3. **The role of the clinical nurse specialist should be emphasized** as part of the support network for patients on AM. Each patient should be provided with the name and contact information of the clinical nurse specialist involved in the diagnosis consultation
4. **Patients should be directed to support networks** such as WMUK and enrolled in the Rory Morrison Registry
5. **A plain language explanation of WM and what is meant by AM should be provided to patients at the point of diagnosis, supported by written information to take away,** ideally during a face-to-face consultation with the WM multidisciplinary team responsible for their care. A patient checklist (**see QR code**), such as the one generated in this analysis, could be offered as part of this process
6. **The multidisciplinary team should consist of HCPs experienced in managing WM.** Where this is not possible, specialist opinion should be sought
7. **Educational materials for HCPs should be provided through a digital platform,** including multimedia formats to increase accessibility. This approach can be supported by patient support networks (eg, WMUK) and pharmaceutical companies where appropriate

The patient checklist can be found by scanning the QR code
AM, active monitoring; HCP, healthcare practitioner; WM, Waldenström macroglobulinemia.

Recommendations to Improve the Experience of AM in WM for Patients and HCPs

- Based on the consensus results, 7 recommendations were created to define AM and give the minimum clinical standards of AM, outline the role and composition of the multidisciplinary team, and identify the need for access to educational materials and support from patient organizations (**Figure 4**)
- A patient checklist of areas to cover during consultation was also generated

REFERENCES

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2. WMUK. Accessed September 17, 2024. https://iwmf.com/wp-content/uploads/2022/01/Rory-Morrison-Report-2021-2-11-21-Final-Version.pdf.

DISCLOSURES

HS: trustee of WMUK. **JN:** Travel, accommodations, or expenses: BeiGene. **CO:** Honoraria and travel: BeiGene; advisory board and travel: AbbVie. **NK:** Employment and may own stock: BeiGene. **SD:** Honoraria: BeiGene, Cellectar; consulting or advisory role: Sanius Health, Cellectar, BeiGene, WMUK; research funding, speakers bureau, travel, accommodations, or expenses: BeiGene. **DT, CB, AM, ZK, JC:** Nothing to disclose.

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Copies of the patient checklist obtained through the Quick Response (QR) code are for personal use only and may not be reproduced without permission from BSH and the authors of this presentation

Patient Checklist

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