

# Patient advocacy group resources improve confidence in managing diagnosis

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**Background:**

Fight Bladder Cancer provides key resources, including a website, patient and carer information booklets, and an online forum, all designed to support individuals diagnosed with bladder cancer. Assessing the effectiveness of these resources in improving patients' and carers' knowledge, confidence, and coping mechanisms is crucial for their continued development. Health literacy plays a pivotal role in enabling individuals to manage their health, and this study aims to evaluate the impact of Fight Bladder Cancer's services on the health literacy of patients and caregivers using the Health Literacy Questionnaire. (Hawkins M et al. BMC Health Serv Res. 2017;17:309).

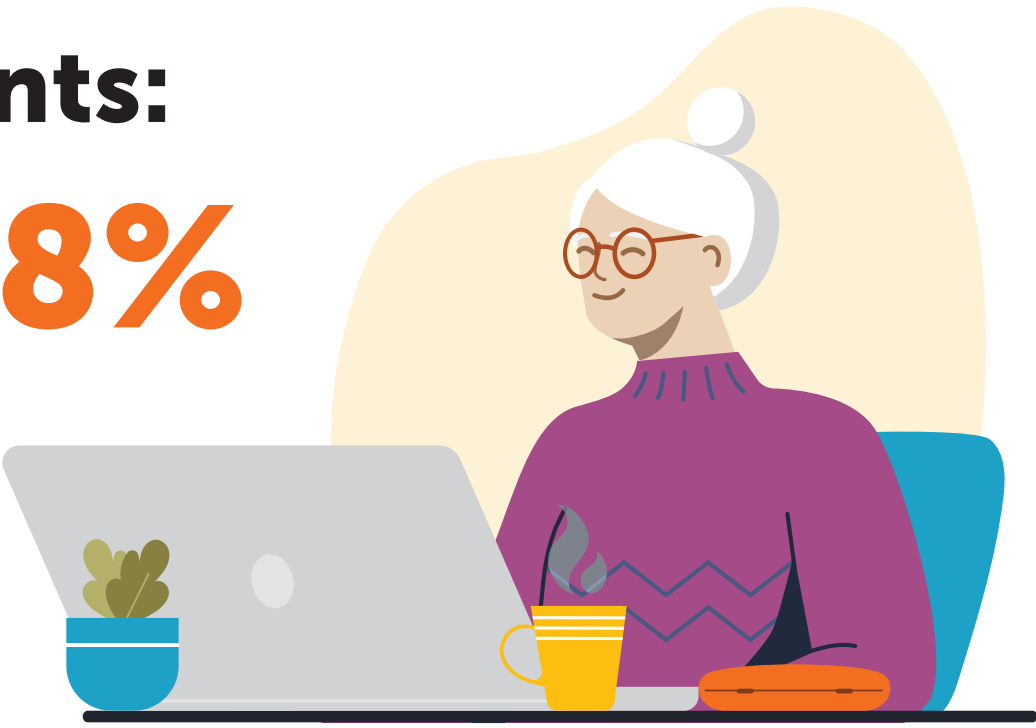
**Methods:**

A survey was conducted with 131 participants, including patients, healthcare professionals, and carers, to assess their experiences with Fight Bladder Cancer services. The survey explored participants' interactions with healthcare providers and any communication challenges they faced. Feedback was collected on the quality of information provided on the website, the usefulness of the patient and carer booklets, and the support offered through the forum.

The Health Literacy Questionnaire is a validated tool designed to measure individuals' ability to access, understand, and use information to manage their health effectively. It consists of multiple domains that explore various aspects of health literacy, including the ability to communicate with healthcare providers, understand medical information, and make informed health decisions. In this study, the Health Literacy Questionnaire was administered to participants following their engagement with Fight Bladder Cancer resources to evaluate how these resources impacted their health literacy and confidence in managing their diagnosis.

## Results: Survey Demographics

**Patients:**  
**86.8%**



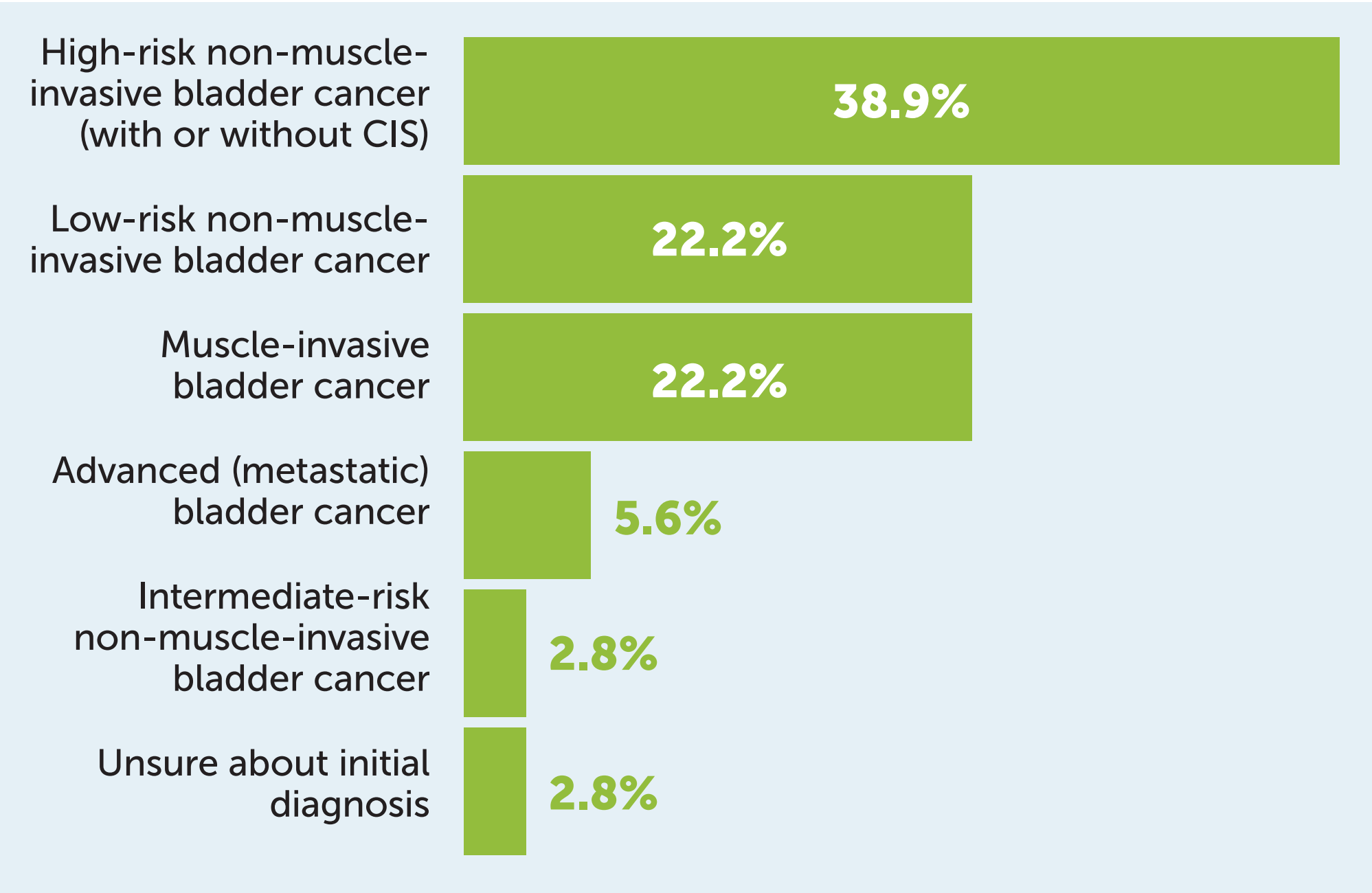
**Healthcare professionals:**  
**9.9%**



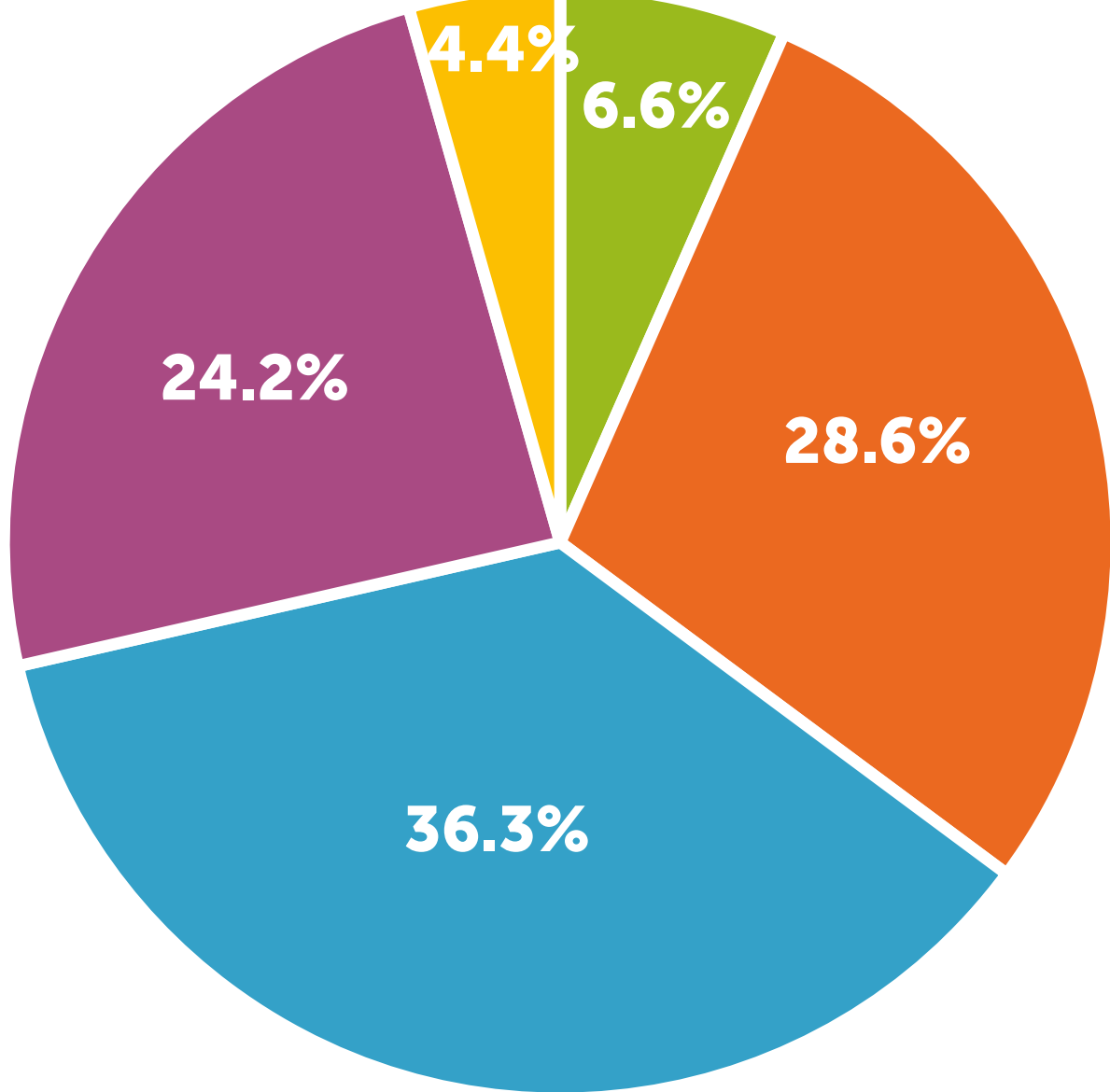
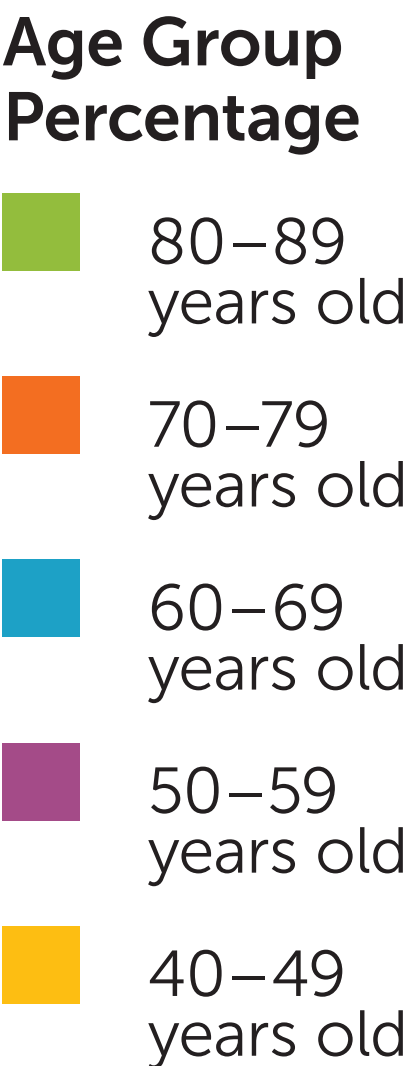
**Carers/spouses/family members:**  
**3.3%**



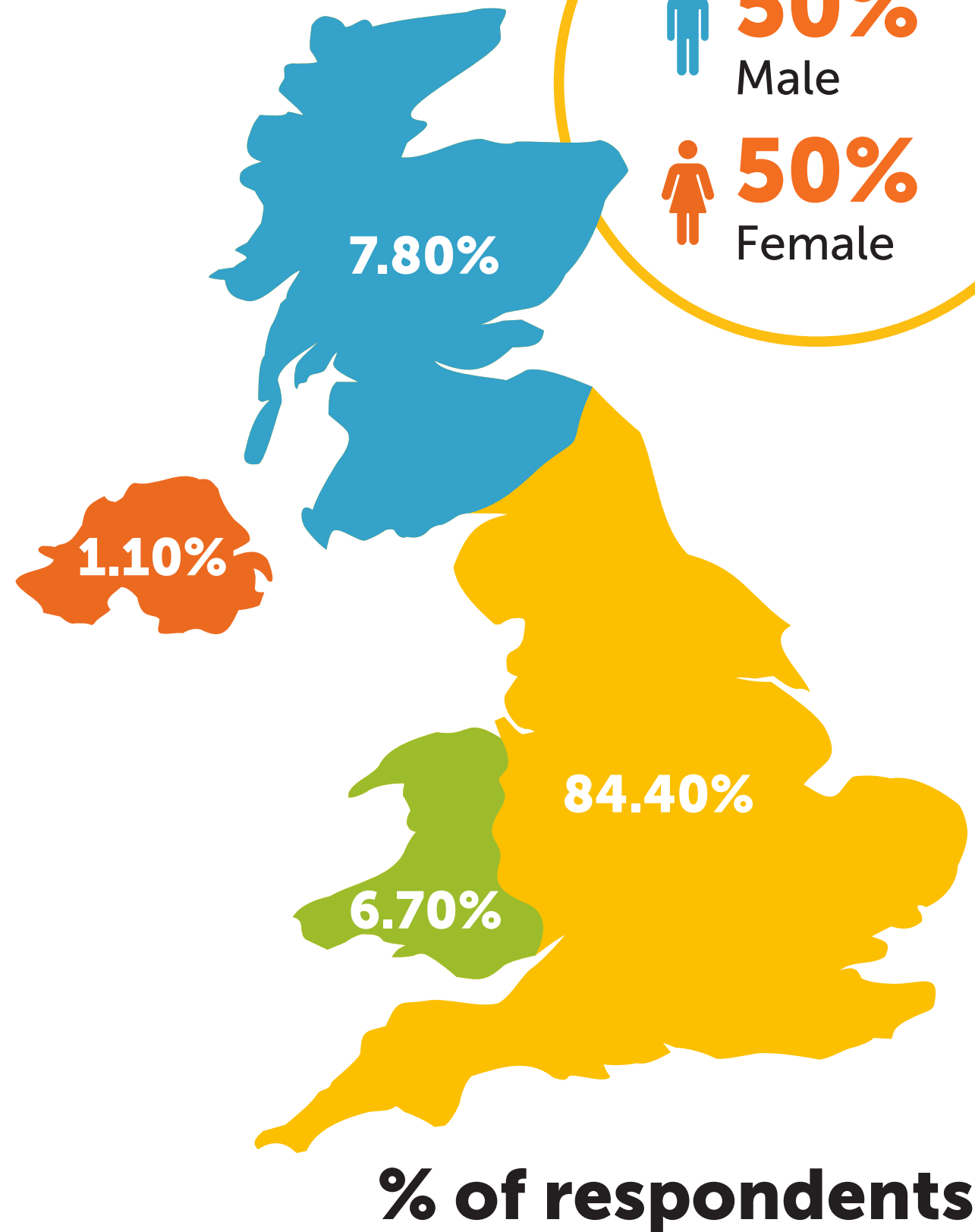
### Initial Diagnosis (Respondents or their loved ones)



### Age Group Distribution of Responses



**Gender:**  
**50%** Male  
**50%** Female



### Fight Bladder Cancer Website Effectiveness

- Quality of information: **84.4%** rated the information as high quality
- Knowledge gained from the website: **83.3%** gained more knowledge
- Confidence in managing the diagnosis: **65.2%** felt more confident
- 31.5%** felt "to some extent"
- Recommendation for newly diagnosed: **96.7%** would recommend the website



### Patient & Carer Information Booklets

- Provided good-quality information: **84.3%** said "yes"
- 14.6%** said "to some extent"
- Knowledge gained from the booklets: **75.6%** reported gaining more knowledge, **23.3%** said "to some extent"
- Confidence in managing the diagnosis: **69.7%** felt more confident, **25.8%** felt "to some extent"
- Recommendation for newly diagnosed: **92.1%** would recommend the booklets, **7.9%** said "maybe"



### Forum Support

- Support in coping with diagnosis and treatment:
- 62.7%** found the forum helpful
- 28.9%** marked "to some extent"
- Impact on well-being during treatment:
- 47.1%** said it improved well-being
- 37.9%** said "to some extent"
- Feeling less alone with the diagnosis:
- 72%** felt less alone
- 15.9%** felt "to some extent"
- 12.2%** said "no"
- Recommendation for newly diagnosed: **89%** would recommend the forum

### Acknowledgments:

We would like to express our gratitude for the generous support of Fight Bladder Cancer services, including personal donations from individuals, community fundraising efforts, in memoriam contributions, and the support of Astellas, Johnson & Johnson, Merck, and Pfizer.

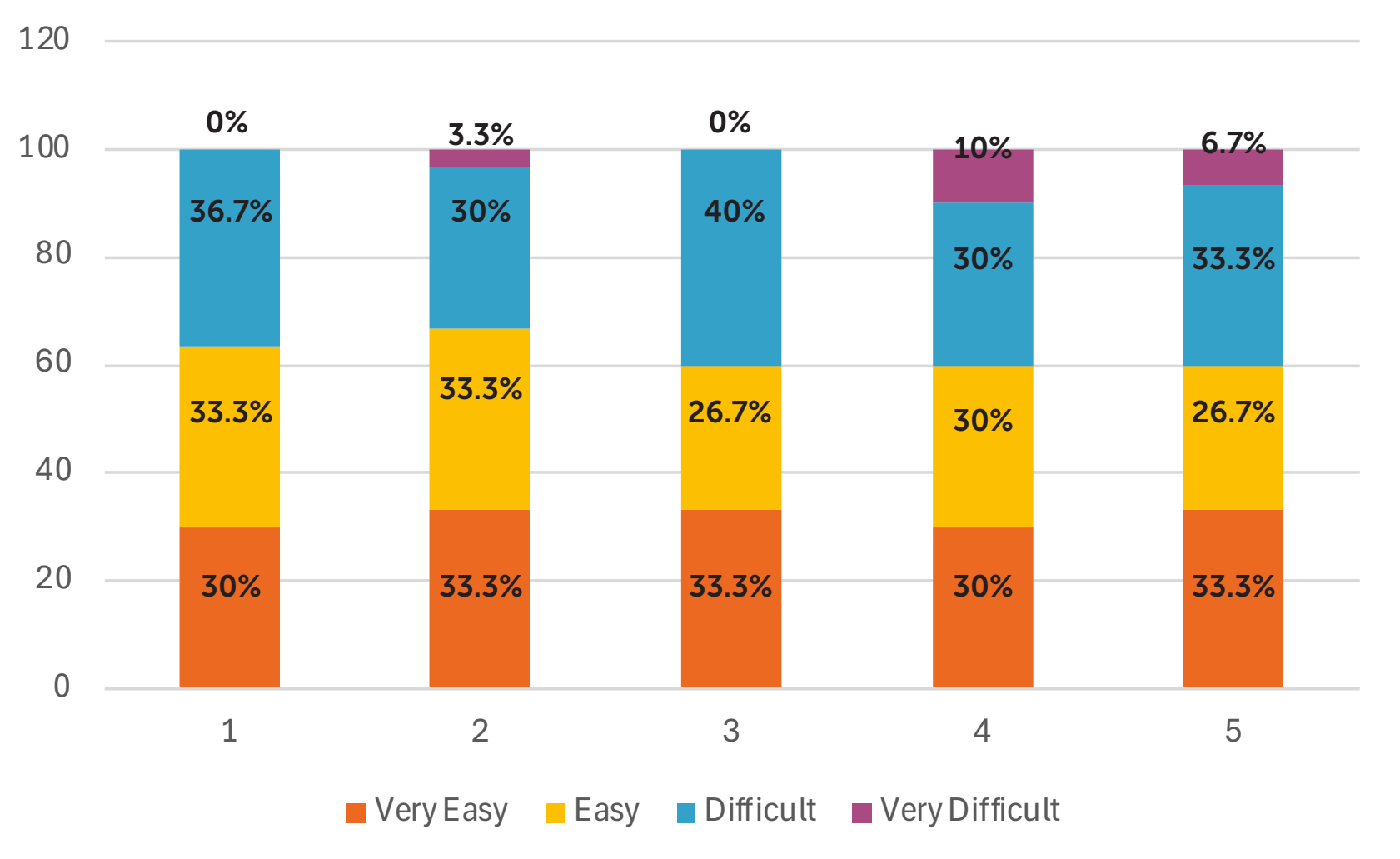
'Good to read other people's experiences and tips. Makes you feel not so alone.'

'Such a useful, supportive group. Feels like a real family.'

'I have found the booklets that you so promptly sent are very informative.'

The responses to the difficulty level of engaging with healthcare providers as assessed by the Health Literacy Questionnaire (Health Literacy Questionnaire). Participants rated their experiences on a scale of Very Easy, Easy, Difficult, and Very Difficult, in response to the question

"How easy or difficult the following tasks are for you to do now?"



- 1 Making sure that healthcare providers understand your problems properly.
- 2 Feeling able to discuss your health concerns with a healthcare provider.
- 3 Having good discussions about your health with doctors.
- 4 Discussing things with healthcare providers until you understand all you need to.
- 5 Asking healthcare providers questions to get the health information you need.

### Conclusions

These results highlight gaps in patients' ability to effectively engage with healthcare providers, despite improvements in health literacy following the use of Fight Bladder Cancer resources. While many participants reported feeling more confident and knowledgeable about managing their diagnosis, challenges persist in ensuring that healthcare providers fully understand patients' concerns so that patients feel equipped to ask relevant questions.

Enhancing health literacy through targeted resources, alongside improved patient-provider interactions, is essential for empowering individuals to manage their bladder cancer more effectively and confidently.

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