

THE EXPERIENCE OF PATIENTS WITH THYMIC EPITHELIAL TUMOURS:

A survey of patient perception of support from their clinical team and beyond

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Introduction

Thymic epithelial tumours (TETs)

- are rare (~ 345 cases diagnosed annually in the UK)
- two main categories: thymoma and thymic carcinoma
- availability and accessibility of formal support for patients is unknown
- number of disease-specific Clinical Nurse Specialists (CNS) is thought to be low; usually incorporated into the lung cancer CNS role
- one registered UK charity dedicated to the disease (ThymicUK)

Methods

- electronic survey
- anonymous
- 10 questions (multiple choice)
- directed at patients in the UK & Ireland
- distributed via the ThymicUK mailing list and closed Facebook group
- data collection over 3 weeks (12/22-01/23)

Results

- 72 participants
- 73.6% female
- from 11 out of 12 UK regions (Fig 1)
- Patient experience varied by UK region (Fig 2-4).
- 50% were diagnosed within the past 2 years (Fig 5).

Figure 1: Where in the UK do you live?

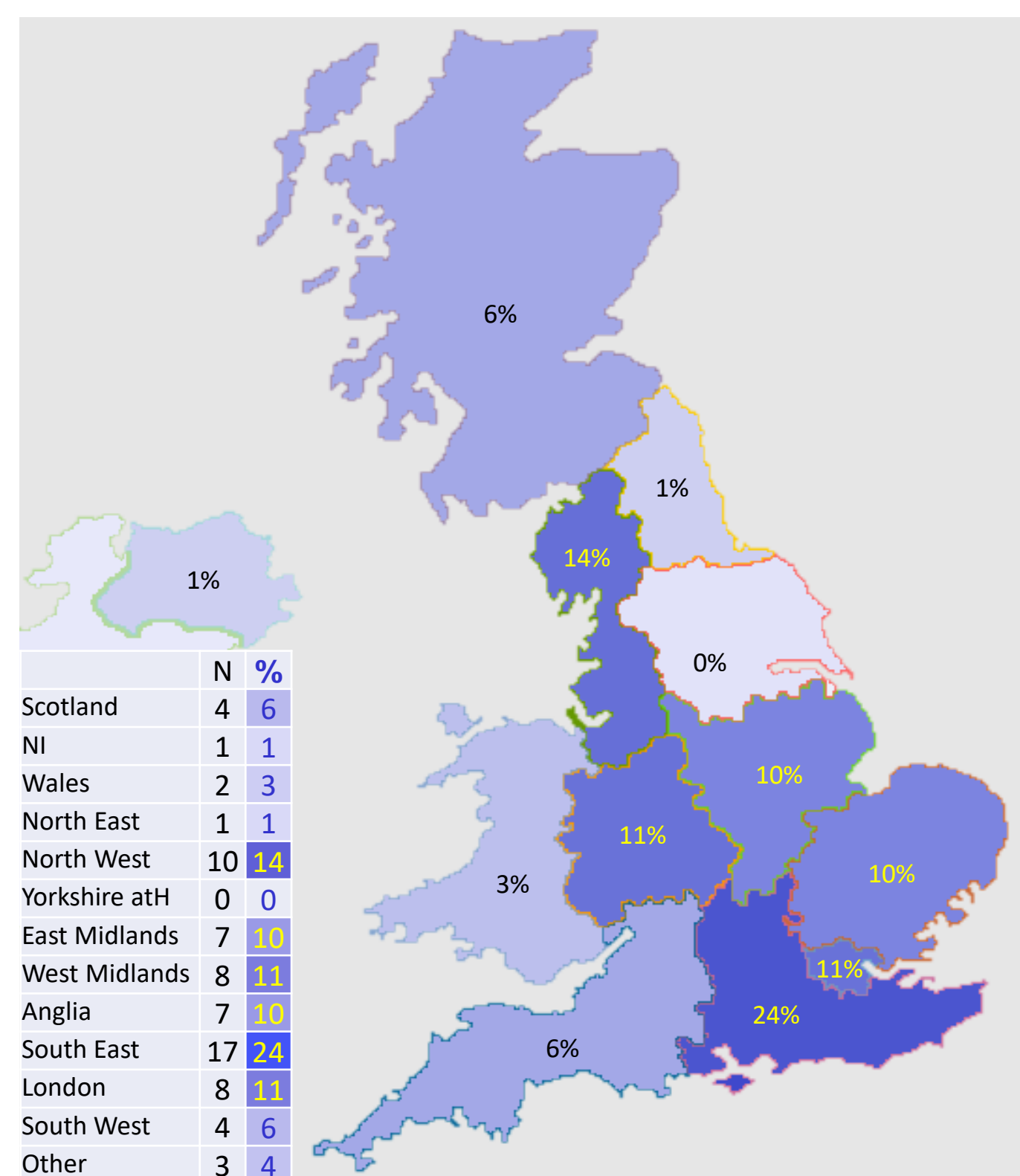
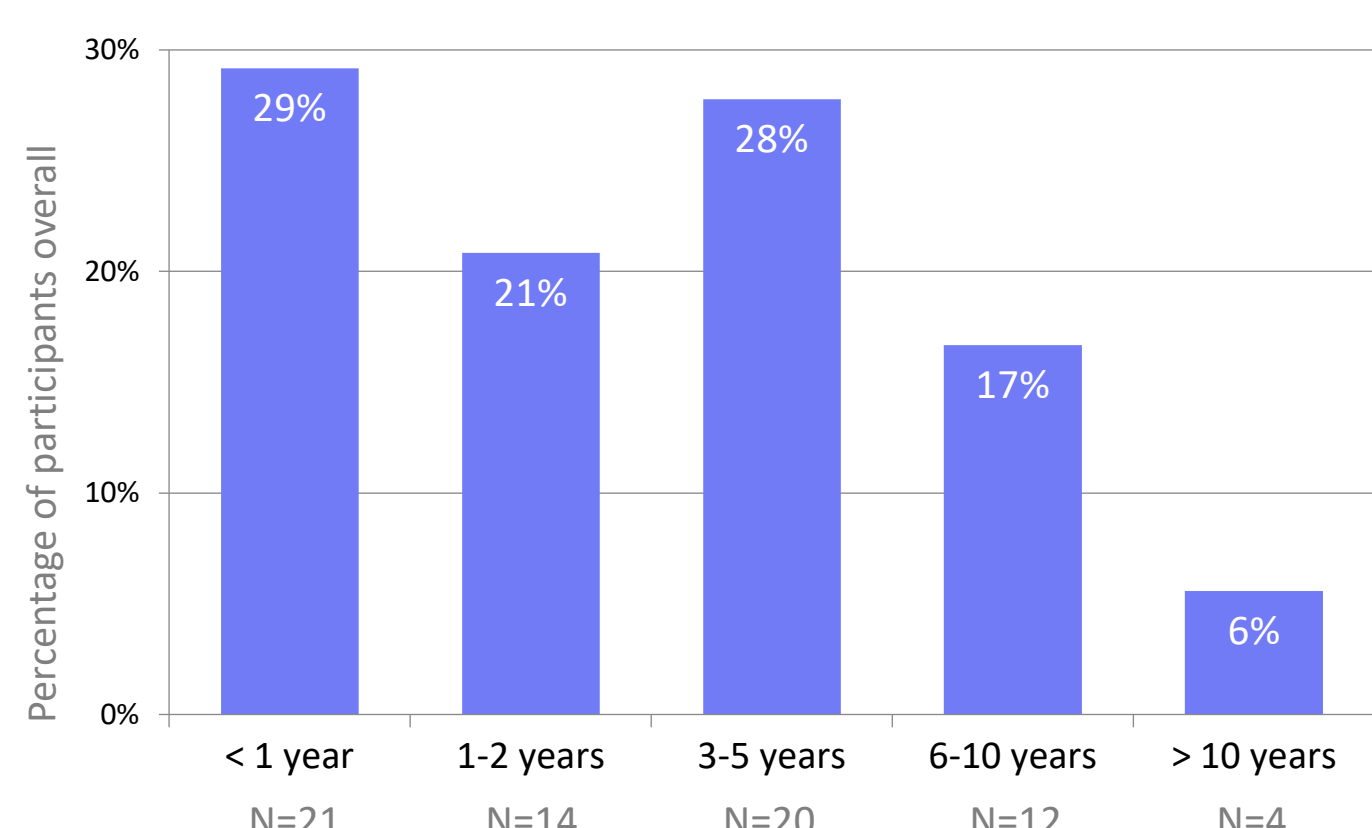


Figure 5: How long ago were you diagnosed?



- 44% were *not* informed that their thymic disease was malignant at time of diagnosis (Fig 2, 7).
- 72% perceived that their (initial) clinician did *not* have adequate experience of managing their disease (Fig 3, 8).
- Asked, whether they feel supported by their medical team, 65% said 'Yes', 7% 'No', and 28% 'Sometimes'.
- 56% have *no* access to a CNS with knowledge of thymic cancers (Fig 4); of those, 55% received *no* signposting to any other source of information or support.
- 18.3% have asked for a second opinion, and 15.5% have asked for a referral (Fig 6).
- There is *no* clear trend of patients' experience improving in more recent diagnoses (Fig 6-8).

Figure 2: When you were initially diagnosed were you told you had cancer?

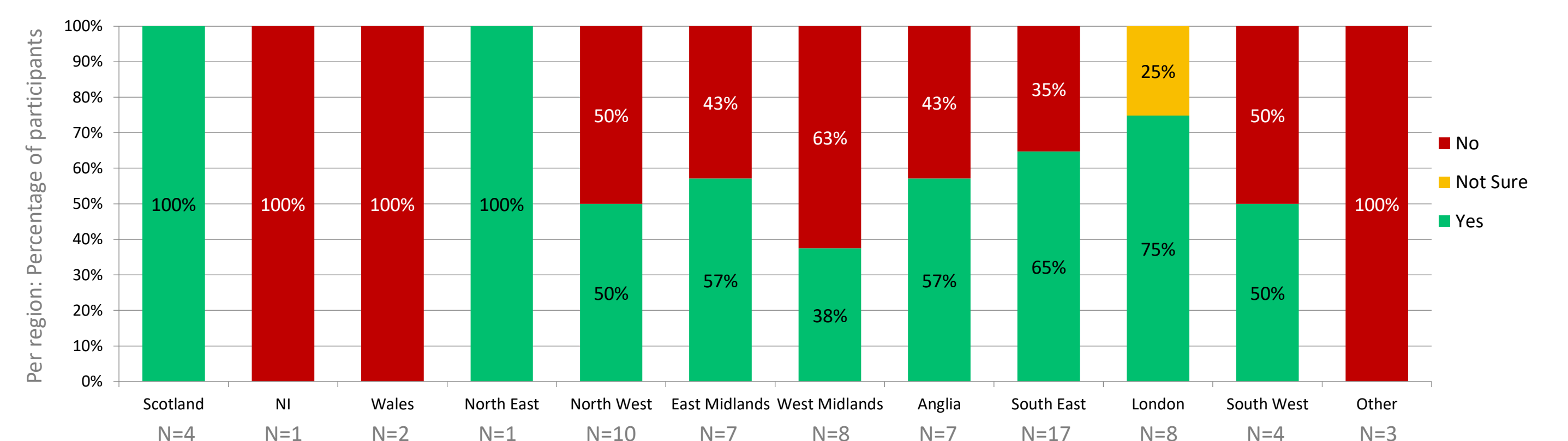


Figure 3: Did your (initial) consultant know about thymic malignancies?

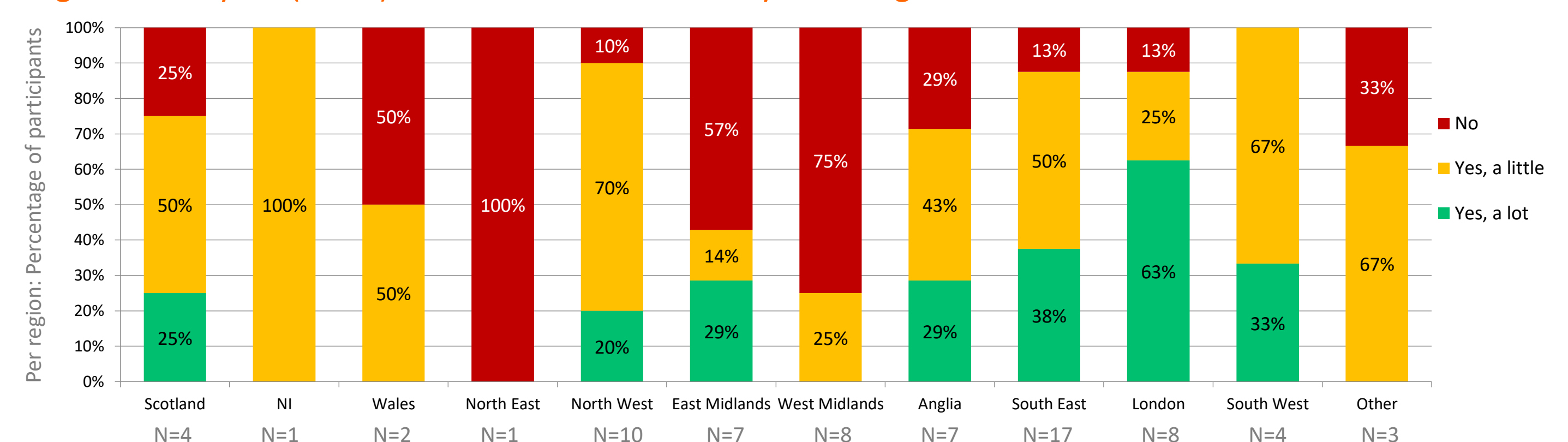


Figure 4: Do you have a specialist nurse with knowledge of thymic malignancies?

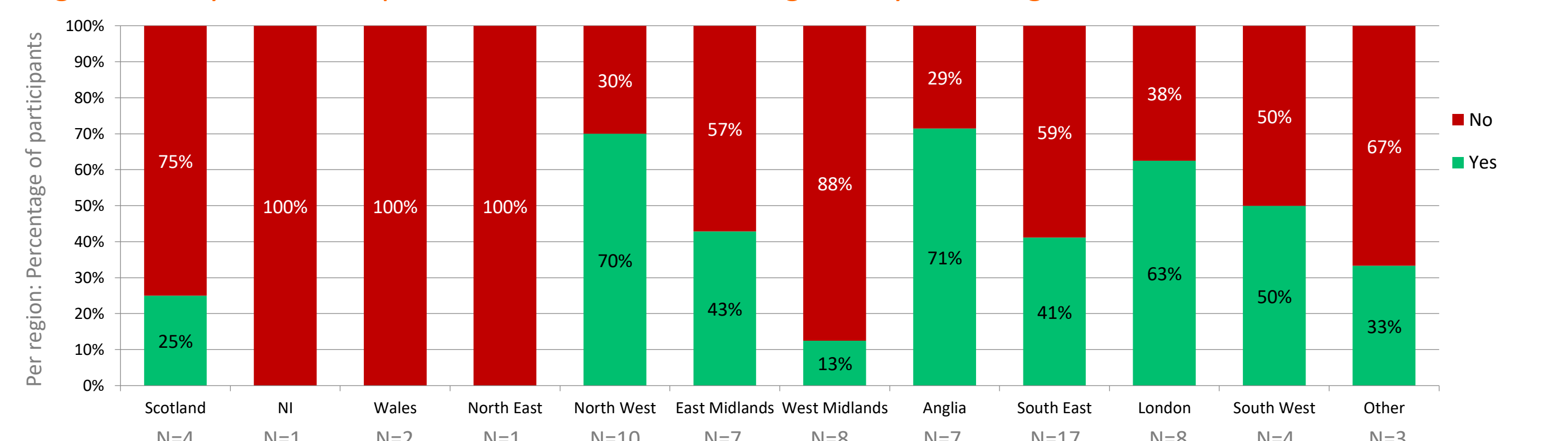


Figure 6: Have you ever asked for a second opinion or a referral? (tick all that apply)

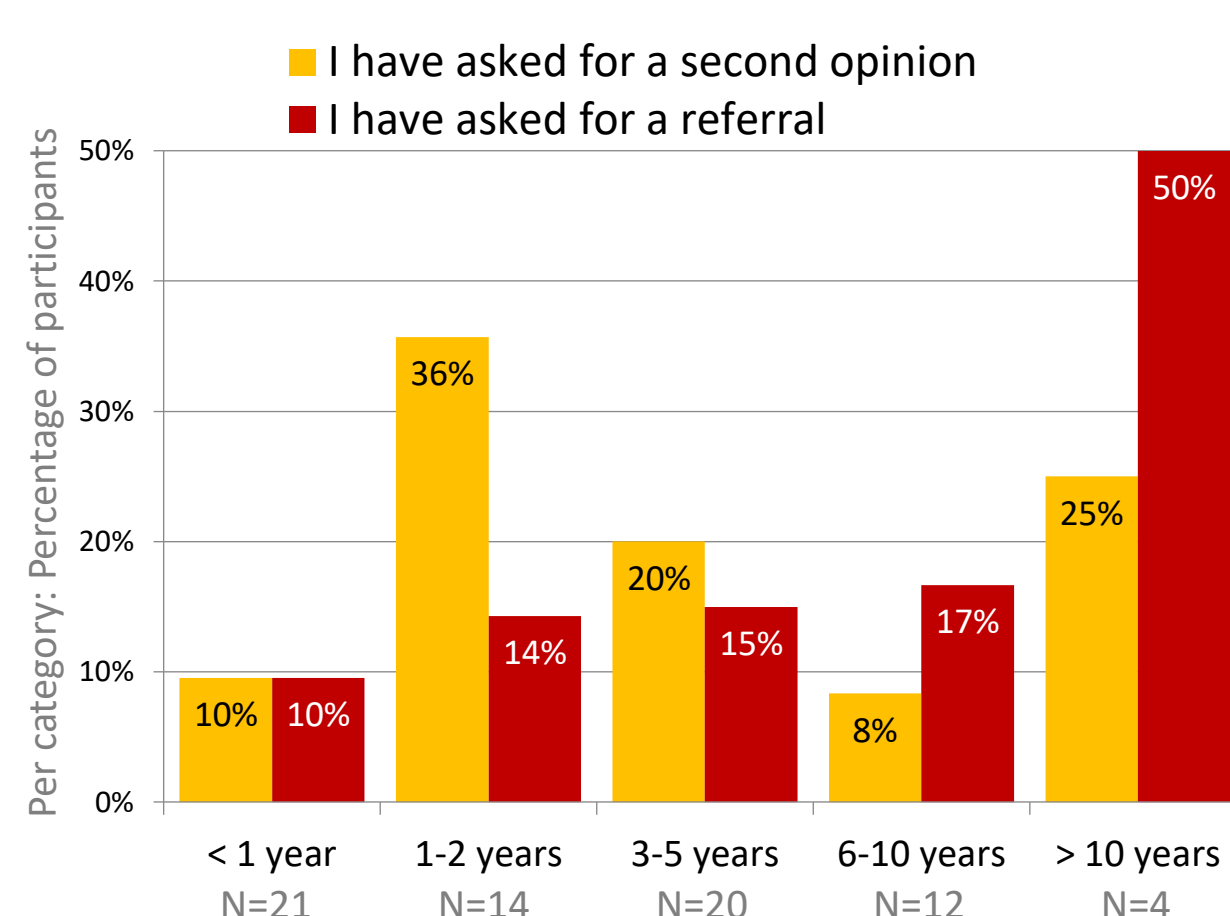


Figure 7: When you were initially diagnosed were you told you had cancer?

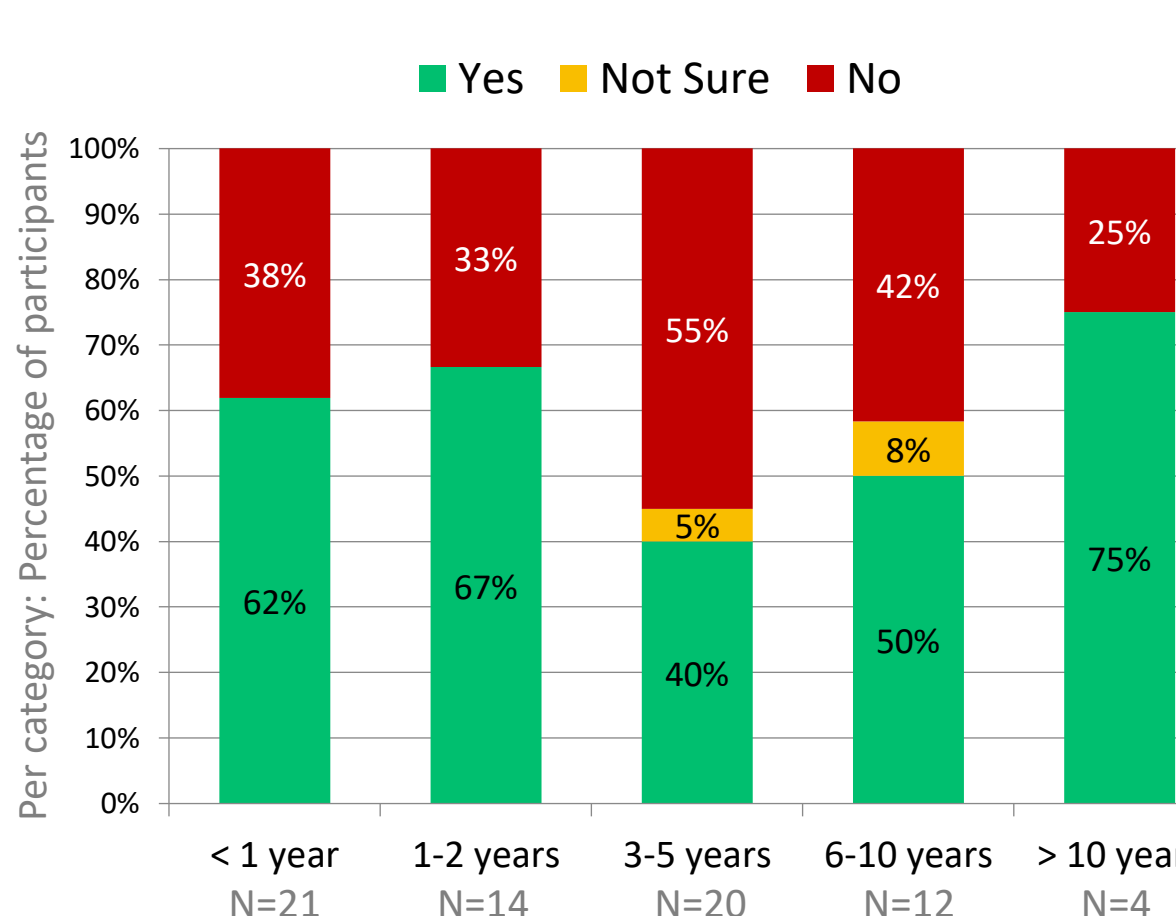
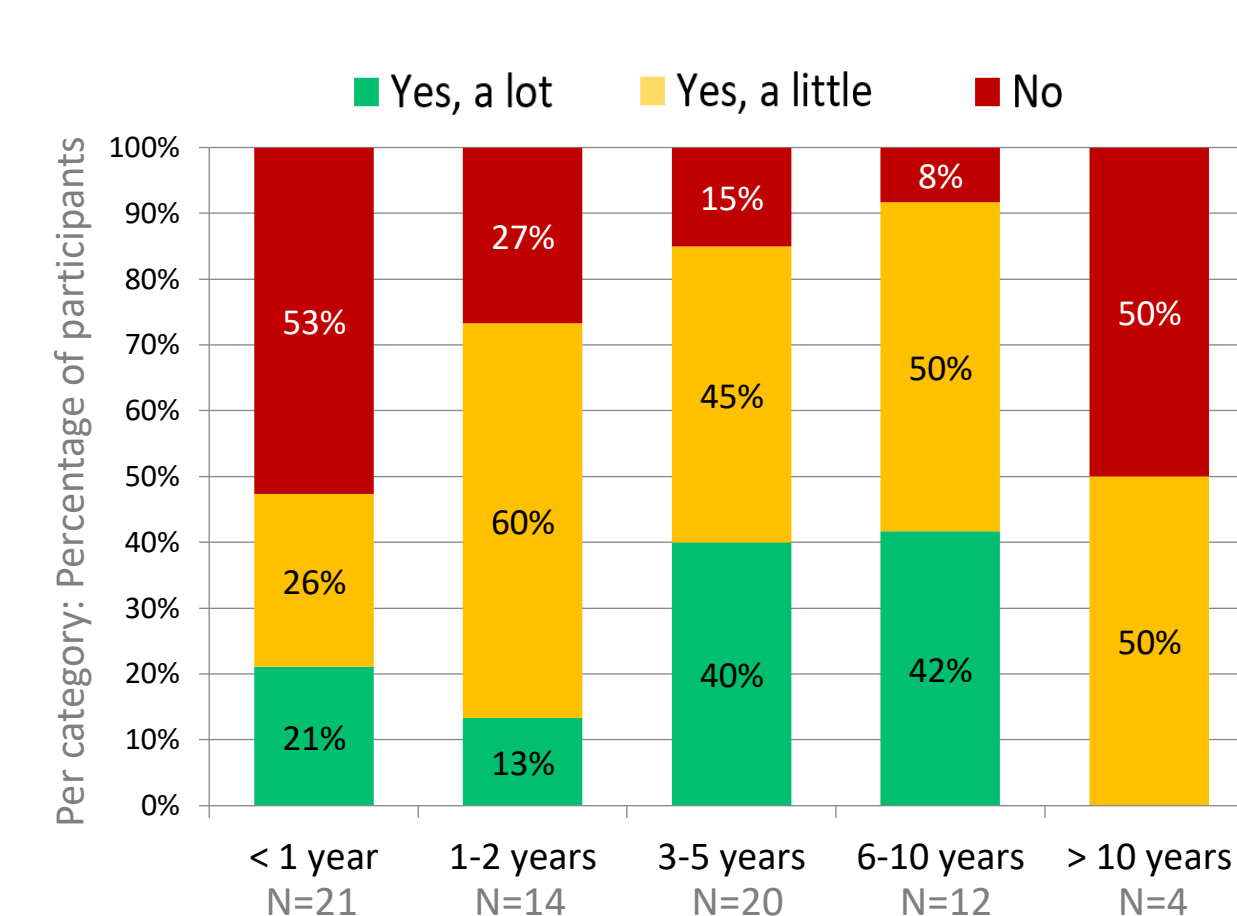


Figure 8: Did your (initial) consultant know about thymic malignancies?



Conclusions

- Patient experience suggests that access to expert clinical advice and holistic support is inadequate and inequitable across the nation.
- Communication should be improved to ensure patients have clarity about their diagnosis and trust and confidence in their clinical team; language used by clinicians may imply a lack of experience or knowledge.
- Individuals should be reassured that although thymic tumours are rare, multidisciplinary working with specialist centres occurs across the UK to ensure appropriate care and treatment is offered.