

## Improving Patient Engagement in Melanoma Clinical Trials

Strategies used to increase patient awareness and comprehension of clinical trials. Perspective from one of the 14 Australian National Cancer Collaborative Groups

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### Background

#### Why melanoma trials are so important in Australia and New Zealand

Australia and New Zealand have the highest incidence of melanoma in the world, almost 14,000 Australians are expected to be diagnosed with melanoma in 2017 (Australian Institute of Health and Welfare 2017)

ANZMTG was established to help develop, conduct and complete clinically relevant, practice changing investigator initiated trials which will improve treatment and survival for people diagnosed with melanoma

#### Problems of recruiting to clinical trials

Often patients are wary of participating in clinical trials due to a number of factors including; varying levels of patient comprehension and health literacy, patients living too far from available clinical trials sites or that patients are simply unaware of the treatment options available to them.

It is important to understand that there are varying levels of patient comprehension even after the consent process has begun.

#### What support already exists

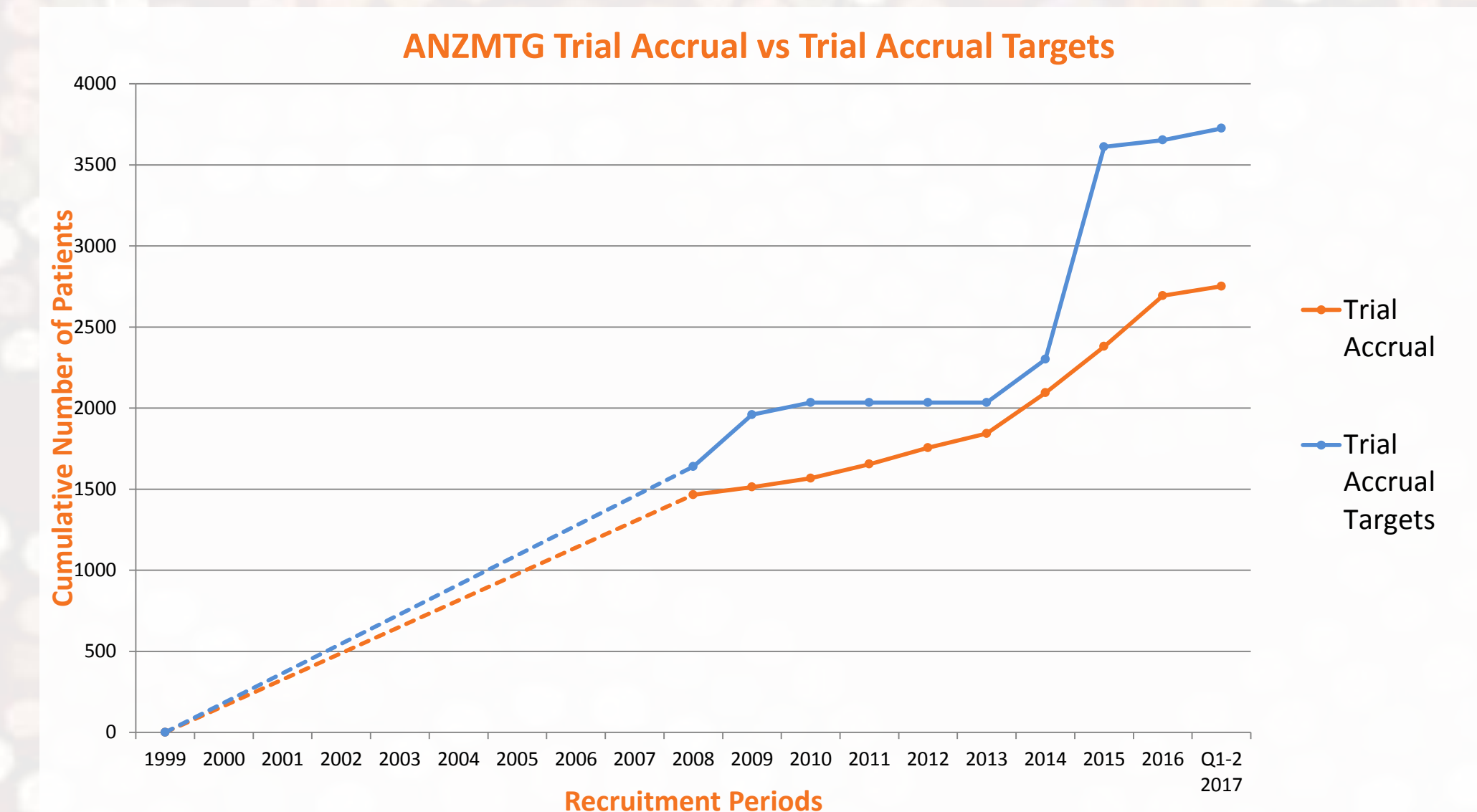
- The first point of contact regarding a clinical trial is usually with the patient's clinician
- Trial specific nursing staff can assist in explaining clinical trials to patients, these staff are often only available in larger metropolitan centres
- Online resources
- Patient advocacy groups
- Clinical Trial Registries

### International Collaboration

When ANZMTG is able to boost recruitment, we are able to boost the possibility for research advancements for patients. Engaging patients in clinical trial research will help achieve this.

ANZMTG has a remarkable track record in the area, having taken part in facilitating 25+ phase II/III trials and having recruited over 2750 patients.

The rapid introduction of new treatments has changed the melanoma clinical trial landscape quickly over recent years. Since 2011, the number of TGA approved therapies used to treat metastatic melanoma has more than tripled.



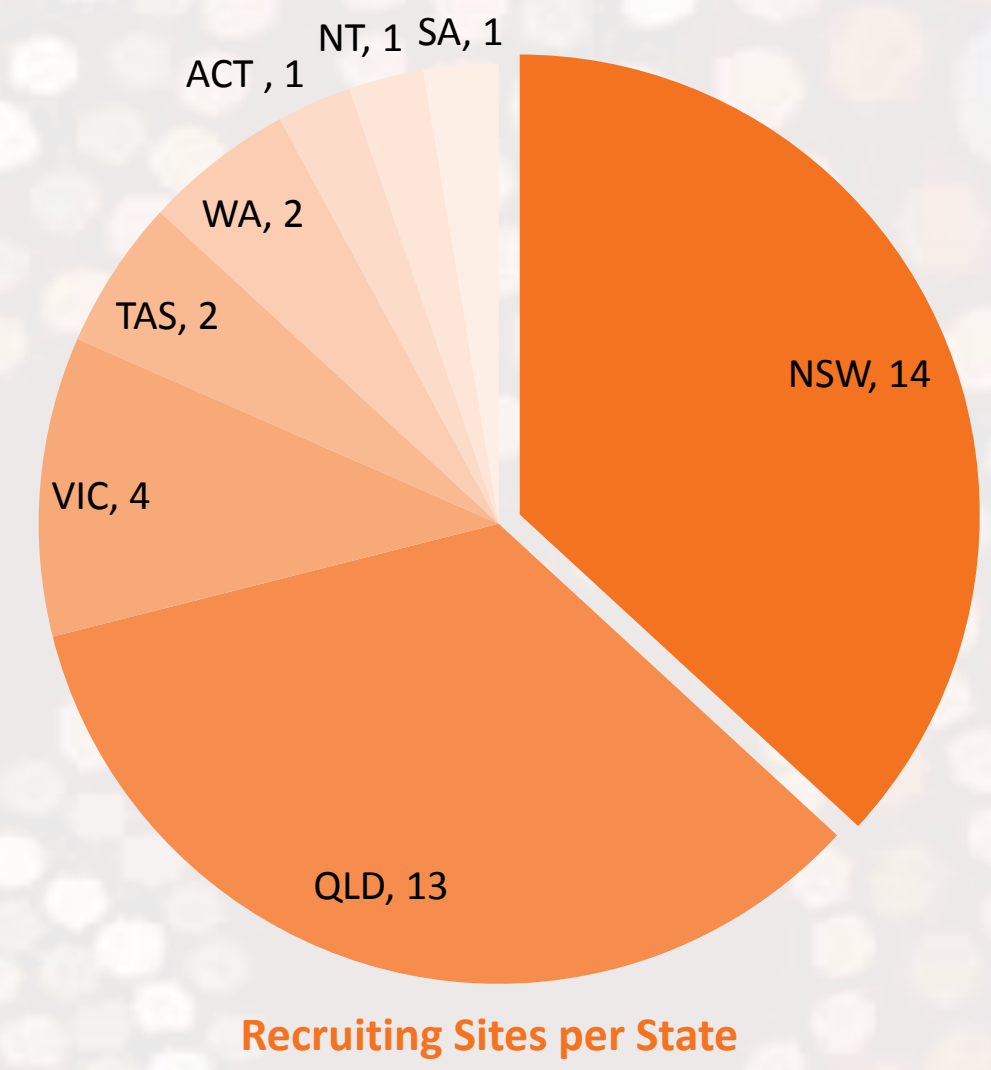
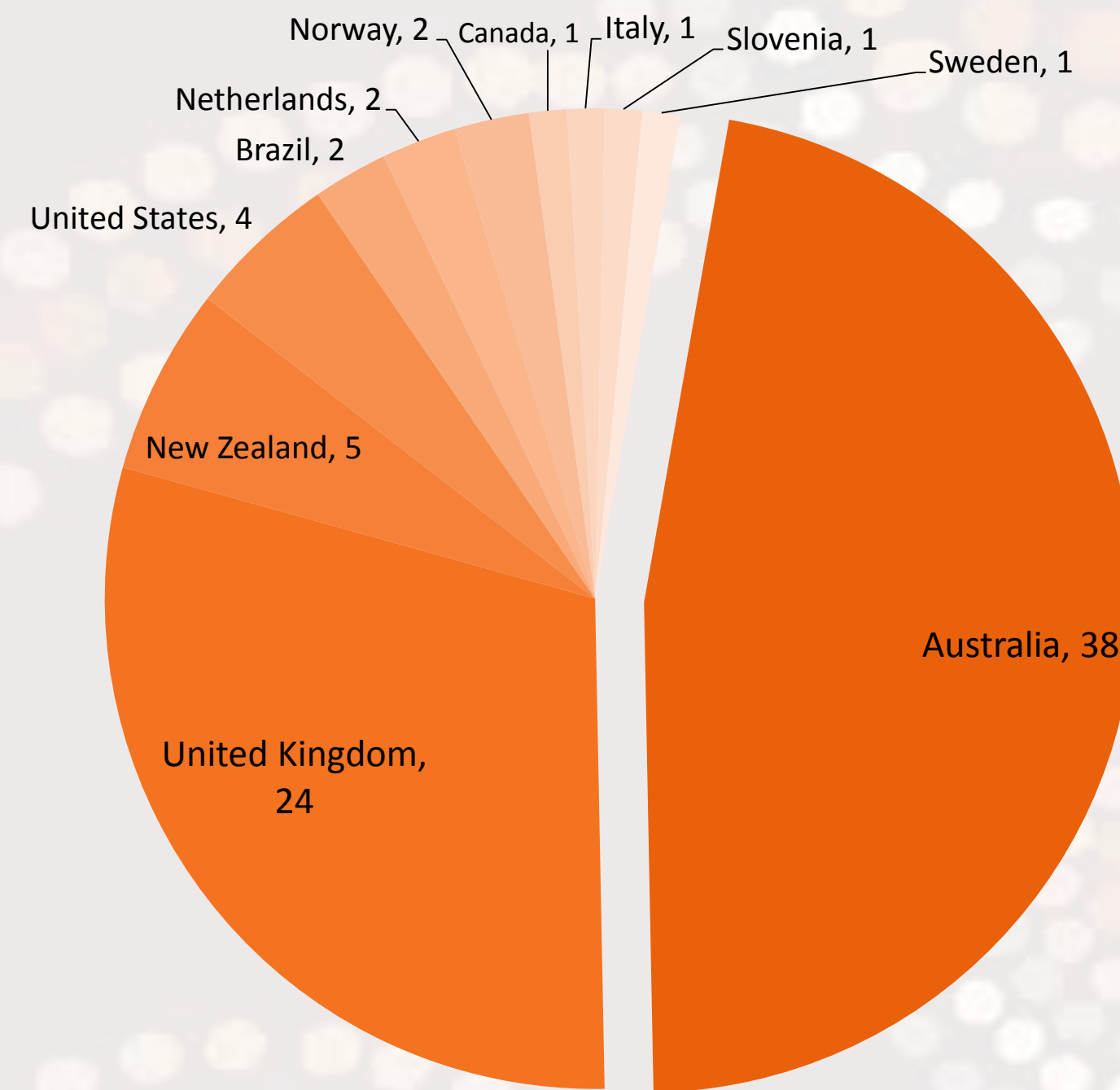
#### ANZMTG Trial Sites

ANZMTG research protocols recruit participants from 81 hospitals around the world, across 11 countries, with 43 hospitals in Australia and New Zealand alone.

#### NSW ANZMTG Trial Sites

NSW is the largest contributor to ANZMTG trials in both membership and trial participation. There are 14 sites in NSW recruiting patients to ANZMTG trials and over 20 sites participating in our research covering 12 of the 15 NSW local health districts.

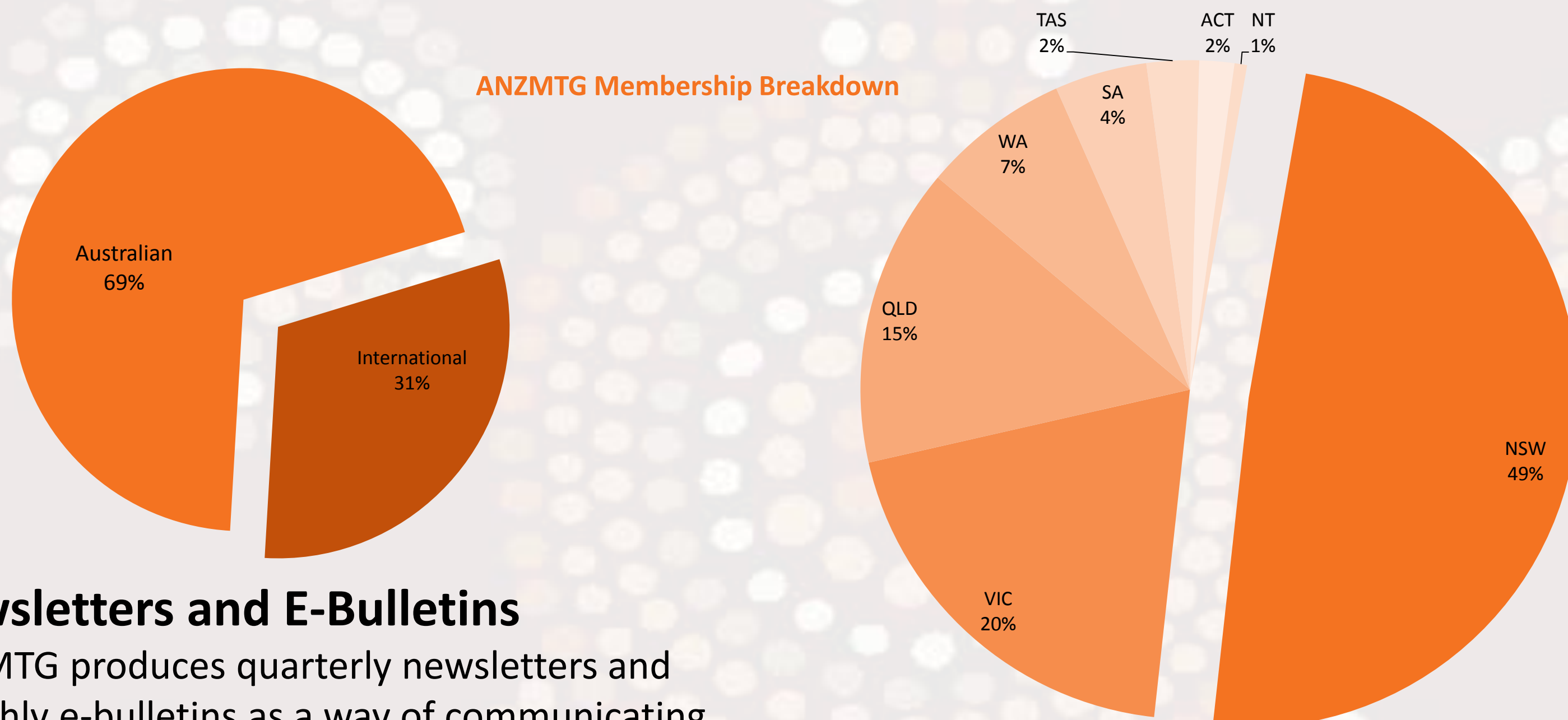
Number of Recruiting Sites to ANZMTG Trials per Country



### Methods

#### ANZMTG communicates with a broad membership

ANZMTG has a membership of over 1200 patients, clinicians and researchers in 30 countries, representing over 380 affiliations globally



#### Newsletters and E-Bulletins

ANZMTG produces quarterly newsletters and monthly e-bulletins as a way of communicating with patients and researchers, to keep them engaged with clinical trials.

#### Consumer Input

ANZMTG works with patient groups such as the Australian Melanoma Consumer Alliance (AMCA) to develop well rounded protocols. AMCA members review protocols and grant applications to ensure participant perspectives in research are involved in trial design.

ANZMTG has embedded an active consumer representative within its governance structure, facilitated through the ANZMTG executive board, to guarantee the review of protocols is equitable and includes multiple perspectives.

#### Website resources

The ANZMTG website hosts valuable information for both patients and clinicians including melanoma resources and links, trial information, news, events and even a statistics portal to help researchers develop trial ideas. The website will become a hub for melanoma clinical trial information.

**Social Media** ANZMTG plans to develop social media to communicate more directly with our members. ANZMTG is developing a series of educational videos and webinar sessions designed to further engage patients and clinicians in our research, these will be distributed through social media networks such as Facebook, Twitter and YouTube as well as being hosted on the ANZMTG website.

#### Funding

We gratefully acknowledge and thank Cancer Australia for their support of ANZMTG



### Educational Videos

#### For Clinicians

ANZMTG has created trial specific education videos across multiple trial protocols, these videos have been created so that clinicians and site staff have a better understanding of the trial processes and can confidently undertake the research.

#### For Patients

ANZMTG has created education videos for patients including videos to explain the clinical trial process and what participation in a particular protocol might involve.

The purpose of producing clinical trial information videos is not to replace or negate the clinician's explanations or the participant information and consent form (PICF) but to add an additional resource for patients, where the standardised information is presented in a different way.

One benefit of providing information online is that it can be referred to multiple repeat times, whenever and wherever is convenient to the patient.

Our YouTube videos have been watched over 35,000 times have been shared in over 20 countries. 46% of our views come from Google or YouTube searches, this shows us that patients are actively seeking out trial information on their own.

#### Patient Education and Advocacy Groups

ANZMTG has convened forums and advocacy groups which serve as an important network to bring together physicians, patients, families and consumer representatives to collaborate and build momentum for research into skin cancers. The most recent of which is the establishment of a Merkel Cell Carcinoma Patient Group.

#### Access to Clinical Trial Information

ANZMTG trials are listed on all of the major clinical trials registries and search apps, such as the ANZCTR, ClinicalTrials.gov and the ClinTrial Refer apps. Patients and clinicians can search for relevant trials and the locations they can participate from

### Conclusion

Through the development of a diverse set of resources for both melanoma patients and clinicians looking to be involved in clinical trials research, ANZMTG is able to assist in providing all potential trial patients access to the same information regardless of location and foster a positive attitude toward clinical trials, along with increasing health literacy among patients, ultimately increasing clinical trial engagement and advancements in research.



#### For further interest

If you are interested to become an ANZMTG member or would like to know more, contact [anzmtg@melanoma.org.au](mailto:anzmtg@melanoma.org.au), ph.: +612 9911 7329; or visit the ANZMTG website [www.anzmtg.org](http://www.anzmtg.org)

