

22 January 2025

Committee Secretary  
Senate Standing Committees on Community Affairs  
PO Box 6100  
Parliament House  
Canberra ACT 2600

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Dear Committee Secretary,

**Re: Inquiry into the access to diagnosis and treatment for people in Australia with tick-borne diseases**

The Royal Australian College of General Practitioners (RACGP) thanks the Senate Standing Committee on Community Affairs for the opportunity to provide comment on the Inquiry into the access to diagnosis and treatment for people in Australia with tick-borne diseases terms of reference.

Australians visit their general practitioner (GP) more than any other health professional. In 2020-21, GPs and their teams provided over 171 million services, with almost nine in ten people consulting a GP.<sup>1</sup> 80% of Australians have a usual GP and 90% have a usual general practice.<sup>2</sup> General practice is well placed to provide patient centred care and support for patients who present with medically unexplained symptoms, which may be challenging to diagnose. As highlighted in the [National Strategic Action Plan for Rare Diseases](#), GPs are one of the key initial points of contact for people with rare diseases. Recognition and support for the role of general practice in the diagnosis and ongoing care of people with tick-borne diseases will ultimately improve the quality of care that patients receive.

We provide comment on the Terms of References below.

- a. *the initiatives and resources developed to improve awareness, diagnosis, treatment and management of tick-borne diseases in Australia since the release in 2016 of the Community Affairs References Committee report Growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients***
- b. *the adequacy and effectiveness of the ‘debilitating symptom complexes attributed to ticks’ clinical pathway to support patients***

The Department of Health and Aged Care has recently published a suite of educational materials to support health professionals on Australian tick-borne illnesses including [guidance notes for health professionals](#) and fact sheets for the general public. These complement the [Debilitating Symptom Complexes Attributed to Ticks \(DSCATT\) clinical pathway](#) and supporting [literature review](#).

While the above guidance is available and welcome, there is still a need for GRADE (Grading of Recommendations, Assessment, Development, and Evaluations) level evidence-based guidelines and patient information. Furthermore, GRADE level guidelines need to be regularly updated as new information and evidence emerges.

Quality evidence-based resources will also assist clinicians and patients by combating existing misinformation. In addition, information and support for positive engagement with the patients and their carers also needs to be developed.

Key areas where GPs need clear information and evidence-based resources include:

- effective prevention strategies

- Q fever vaccination (to be able to assist people who are at risk of exposure to the Q fever bacterium)
- first aid strategies for tick bite
- information about post-exposure prophylaxis
- the range of symptoms and signs associated with tick-borne subacute and chronic infections
- effective, affordable and accessible diagnostic tests
- evidence-based treatment algorithms
- information to provide returned travellers with suspected Lyme disease and similar conditions.

#### **c. current research to advance the management of complex inflammatory diseases**

Adequate funding needs to be provided for Australian-specific research and research synthesis. The recently established [Australian Centre for Disease Control](#) (CDC) is best placed to support this.

#### **d. any other related matters**

##### Diagnostic uncertainty and low value care

GPs are one of the key initial points of contact for people with rare diseases, such as tick-borne illnesses, and need to be alert and aware of when to investigate for rare causes when a patient presents with symptoms and signs that can be difficult to define and diagnose. GPs will also be aware these illnesses could affect a patient psychologically as well as physically and are well placed to coordinate multidisciplinary care.

GPs work to understand and respect patient concerns and preferences as they work towards a diagnosis and timely treatment. Balancing patient expectations, whilst negotiating diagnostic uncertainty, can be challenging and we recognise this can be frustrating for patients.

Submission 3.16 in the 2016 Senate Standing Committees on Community Affairs [Senate final report](#) (p34) highlights some of the challenges. It found that in people presenting with Lyme-like illnesses:

- *30-50% have potentially serious medical conditions that have either been previously undiagnosed, diagnosed but inappropriately treated, or diagnosed but denied by the patient such that no treatment was sought.*
- *10-20% have a serious defined psychiatric illness that requires specialist care*
- *80-90% have undergone substantial financial hardship paying for investigations from unaccredited laboratories and, in some cases, prolonged antibiotic treatment that has had no (or minimal) objective evidence of benefit.*

This illustrates that misdirected care can lead to underdiagnosis of overlapping conditions and expensive diversion of patient and clinical resources.

We need to be mindful that unnecessary medications, testing or procedures are low value care and can cause more harm than benefit. As there is currently little or no evidence to support specific treatments for tick-borne diseases, it is important that all patients have access to and are provided with safe and high-quality care. To address this:

- authorities such as the Therapeutic Goods Administration (TGA) should consider ways to reduce access to low value or harmful treatments.
- government funded information services, such as Health Direct, could provide evidence-based information that aims to prevent vulnerable people being financially and physically harmed by low-value treatments.
- investment is needed in research and GRADE level clinical guidelines.



The rest of the health system

There should be some alignment between guidance provided in the veterinary and agricultural sectors and human health sector

Thank you again for the opportunity to provide a submission to the Inquiry into the access to diagnosis and treatment for people in Australia with tick-borne diseases. If you have any questions regarding our submission, please contact Mr Stephan Groombridge, National Manager, e-health, Quality Care & Standards at [stephan.groombridge@racgp.org.au](mailto:stephan.groombridge@racgp.org.au) or 03 8699 0544.

Yours sincerely

Dr Michael Wright  
President

References

1. *Australian Institute of Health and Welfare. Chronic conditions and multimorbidity. Australian Government; [updated 14 Dec 2023; accessed 2024 12 April 2024]. Available at <https://www.aihw.gov.au/reports/australias-health/chronic-conditions-and-multimorbidity>*
2. *Australian Department of Health. Annual Medicare Statistics – Financial Year 1984-85 to 2019-20. Canberra: Department of Health; 2020*