



Australian Government

Australian Government response to the
Senate Community Affairs References Committee report:

*Access to diagnosis and treatment for people in Australia with
tick-borne diseases*

OCTOBER 2025

Overview

The Australian Government appreciates the opportunity to respond to the Senate Community Affairs References Committee list of recommendations on the Access to diagnosis and treatment for people in Australia with tick-borne diseases. The Government thanks the Committee and the various stakeholders for their valuable and thoughtful input to the Inquiry.

The Government acknowledges the concerns of patients who are facing issues accessing diagnosis and treatment with tick-borne illnesses. In early 2013, the Department of Health, Disability and Ageing began engaging with patients, medical practitioners, and advocacy groups to discuss concerns about Lyme disease. In 2016, the department engaged and addressed the Senate Inquiry recommendations into Growing evidence of an emerging tick-borne disease that causes a Lyme-like illness (2016 Inquiry) through a range of measures such as public education materials, research and guidance for medical practitioners. As a result, the department has gained a deeper appreciation and growing concern for those Australians experiencing issues relating to tick-borne diseases.

This response addresses the specific recommendations raised in the current Senate Committee's Report. The Government remains open-minded about the cause of the various complexes which manifest as a range of chronic debilitating symptoms. The best outcome for patients and health practitioners is to not draw conclusions based on poor levels of evidence, but to consider each patient thoroughly in a multidisciplinary medical approach that makes the best use of clinical expertise and available diagnostic skills and technology.

The Government remains engaged with the patient and medical community to continue to find, share and understand the evidence associated with tick-borne diseases. The Government hopes its continued work with clinical medicine and research communities will result in answers and relief for patients and their families.

Recommendation 1

The committee recommends that the Department of Health, Disability and Ageing work with state and territory governments to develop public education and awareness campaigns to prevent tick-bites, provide information on the treatment of tick-bites, and the symptoms of tick-borne illnesses.

The Government supports this recommendation.

In the first instance the department will work with state and territory governments to review existing public education materials on the prevention of tick-bites, treatment of tick-bites, and the symptoms of tick-borne illnesses.

Following the recommendations of the 2016 Inquiry, the department engaged Allen and Clarke Consulting to produce a suite of tick educational materials. This included fact sheets for the general public and guidance notes for clinicians. Tick educational materials are available on the department's website. Fact sheets and guidance notes on the topic of tick-borne diseases describe best practice principles for tick prevention and tick bite management.

Recommendation 2

The committee recommends that the Department of Health, Disability and Ageing fund research to collect data on the prevalence, frequency and geographical distribution of tick bites in Australia.

The Government notes this recommendation.

It is not economically nor practically feasible to track all tick bites in Australia, nor would it be for any other vector bite such as mosquitoes.

The department manages the Nationally Notifiable Disease Surveillance System (NNDSS) that provides coordinated national surveillance data for over 70 diseases on the [National Notifiable Disease List](#) (NNDL). Unspecified tick-borne infections are not notifiable and unlikely to meet the criteria, including presenting a risk to public health if there is an outbreak, to warrant the addition to the NNDL.

The Government will explore sampling surveys that could track some epidemiology of tick bites.

Recommendation 3

The committee recommends that the Department of Health, Disability and Ageing consult medical practitioners and patient stakeholder groups to develop a term to replace Debilitating Symptom Complexes Attributed to Ticks (DSCATT) that removes the stigma that is felt by patients, and provides clarity for medical practitioners.

The Government supports this recommendation in principle.

Following the 2016 Inquiry, the department strongly supported the removal of the terms “Lyme Disease”, “Lyme disease like Illness” and “Chronic Lyme Disease” from diagnostic discussions. As there was no clear agreed alternative nomenclature, the department proposed to use the term “Debilitating Symptom Complexes Attributed to Ticks” (DSCATT). NHMRC adopted the term for its Targeted Call for Research, to describe the heterogeneous nature of the debilitating symptom subgroups with an acknowledgement that ticks may have a role.

Since then, DSCATT has been a term used by the Government to describe the group of Australian patients suffering from the symptoms of a chronic debilitating illness, which many associate with a tick bite. It has been used to appropriately acknowledge this patient group and the multifaceted illness they are experiencing, and acknowledge their illness is poorly understood based on the available evidence. DSCATT was also proposed as a name to move away from the stigma and controversy associated with the terms previously used to describe this patient’s group such as “Lyme disease-like Illness” and “Chronic Lyme Disease”.

The Government will explore the implementation of this recommendation with medical practitioners and patient stakeholder groups accordingly. The department stresses that all terms must provide an accurate description, be acceptable, and not mislead or contribute to misinformation or disinformation.

Recommendation 4

The committee recommends that the Department of Health, Disability and Ageing replace the DSCATT Clinical Pathway with Grading of Recommendations, Assessment, Development and Evaluations (GRADE) guidelines and patient information.

The Government supports this recommendation in principle.

The Government understands from the public hearing as well as the submissions from experts, that the recommendation is to ensure the clinical pathway document contains and explains the level of evidence used in the development of a clinical pathway document. The Government acknowledges this approach will provide transparency about the quality of the evidence in the clinical pathway document.

The Government notes that the DSCATT Clinical Pathway was developed to support decision-making in diagnosing and referring patients presenting with either new onset or unresolved debilitating symptoms with or without a history of tick bites that cannot be attributed to another condition. The evidence-based DSCATT clinical pathway and multi-disciplinary care model for patients presenting with DSCATT helps doctors to make diagnoses and referrals for DSCATT patients.

Patient groups were consulted during the development of the DSCATT Clinical Pathway, as were medical and scientific experts. The DSCATT Clinical Pathway was considered by subject matter experts and was provided to the then Australian Health Protection Principal Committee and relevant subcommittees prior to publication. Overall, the DSCATT clinical pathway was well accepted and viewed as a valuable resource, particularly among authoritative medical and government health authorities. The Government understands there is dissatisfaction on the Clinical Pathway among some stakeholders and is open to exploring this recommendation.

Recommendation 5

The committee recommends that the Department of Health, Disability and Ageing review its suite of fact sheets for the public, and guidance notes for practitioners, to ensure that they are fit for purpose.

The Government supports this recommendation.

The Government acknowledges the dissatisfaction expressed in the report in relation to tick illness related information that is available for the public and practitioners. The Government is committed to reviewing the fact sheets to ensure that they are patient centred and support practitioners to provide suitable care.

Recommendation 6

The committee recommends that the Australian Government provide funding for urgent research to identify and treat tick-borne diseases, including through: the identification of tick-borne pathogens in Australia; determining whether these pathogens are transmissible to humans; and evaluating the efficacy of treatment protocols accessed by patients both domestically and internationally.

The Government supports this recommendation in principle.

Following the 2016 Inquiry the department urgently funded a targeted call for research to identify and treat tick-borne diseases. This includes recently published research by the CSIRO and the National Health and Medical Research Council currently in progress. The Government will consider the findings of current research, including the CSIRO's findings that after extensive research, no Lyme disease causing *Borrelia* species was found in Australia. Any future investment and potential research will build on the evidence available,

rather than further exploring borrelia as a vector for DSCATT in Australia. This reduces the risk of duplication and ensures investment in targeted research to identify gaps, including through projects funded by the National Health and Medical Research Council.

Recommendation 7

The committee recommends that the Government urgently review diagnostic testing available internationally to determine the efficacy and suitability for use in Australia.

The Government supports the recommendation in principle and will engage with pathology expert groups to seek advice.

The Government acknowledges the contributions made from witnesses with interests in the testing methodologies available internationally. The Government supports the recommendation in principle and will engage with pathology expert groups to seek advice.

The Government notes that:

1. It would not be viable for the Government to adopt international diagnostic devices that target international pathogens not identified in Australia to date.
2. Current research has not found evidence of Lyme disease to occur indigenously in Australia.
3. The importation of diagnostic devices targeting non-indigenous pathogens in Australia is therefore not deemed feasible.

The department maintains familiarity with testing methodologies used internationally and keeps abreast of the available diagnostic approaches to help determine suitability for use in Australia.