

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

Submission by the Department of Health and Aged Care
to the Senate Standing Committees on Community Affairs

1. Introduction

The Department of Health and Aged Care, through the Interim Australian Centre for Disease Control, welcomes the opportunity to make a submission to the Senate Standing Committees on Community Affairs regarding *Access to diagnosis and treatment for people in Australia with tick-borne diseases*.

Debilitating symptom complexes attributed to ticks (DSCATT) is the term used by the Australian Government to describe the group of Australian patients suffering from the symptoms of a chronic debilitating illness which they have associated with a tick bite.

Lyme disease is caused by the bacteria *Borrelia burgdorferi*. Scientists have not found *Borrelia burgdorferi* bacteria in Australian ticks despite extensive surveys and research. Unless compelling scientific evidence verifies the presence of *Borrelia burgdorferi* bacteria in Australia or the native *Borrelia* species is shown to cause Lyme disease, the Australian Government is not in a position to support the diagnosis of locally acquired Lyme disease. The Australian Government's position is accepted by most conventional medical practitioners and the scientific community, based on the available evidence.

As a result, in Australia, Lyme disease is only considered clinically relevant in patients with an international travel history to a Lyme disease-endemic area, who are experiencing supporting symptoms, and/or a verified tick bite, and/or laboratory test results performed by an accredited laboratory¹. This position is supported by both the Royal College of Pathologists of Australasia and the Royal Australasian College of Physicians.

2. Inquiry Terms of Reference

- 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.**

All recommendations of the 2016 Inquiry have been addressed (Attachment A). The main activities include:

- an evidence-based clinical pathway and multidisciplinary care model for patients presenting with DSCATT.
- education and awareness resources to help health professionals and the public.
- research by the Commonwealth Scientific and Industrial Research Organisation (CSIRO) including to better understand the bacteria, viruses and other pathogens carried by ticks as well as the effects of these pathogens on human health.
- grants by the National Health and Medical Research Council through a Targeted Call for Research to:

¹ Lum GD et al. An Australian guideline on the diagnosis of overseas-acquired Lyme disease/borreliosis. *Commun Dis Intell Q Rep.* 2015 Dec 31;39(4):E590-6. PMID: 26779732.

- The University of Melbourne to explore new research for treating unexplained syndromes linked to tick-bites in a randomised trial.
- Murdoch University for research on causes of DSCATT.
- a one-off grant to the Lyme Disease Association of Australia for advocacy and crisis counselling services for patients presenting with DSCATT.

In addition to research funding, Allen and Clarke consultants were engaged to produce a DSCATT Clinical Pathway to support clinicians to make diagnoses and referrals for patients presenting with chronic symptoms attributed to an unknown illness, and a suite of educational materials including fact sheets for the public and guidance notes for clinicians.

The DSCATT Clinical Pathway and tick educational materials are available on the department’s website. Fact sheets (for the general public) and guidance notes (for clinicians) on the topic of tick-borne illnesses are available and include those listed in Table 1. The guidance notes provide information on DSCATT and tick-borne diseases and describe best-practice principles for tick prevention and tick bite management. Links to resources on overseas-acquired tick-borne illnesses are also available.

Table 1 – List of fact sheets (for the general public) and guidance notes (for clinicians) on the topic of tick-borne illnesses

FACT SHEETS
Queensland Tick Typhus (QTT)
Q Fever
Flinders Island Spotted Fever (FISF)
Australian Spotted Fever (ASF)
Lyme disease
Prevention of tick bites in Australia
Serious allergic reactions from tick bites
Paralysis from tick bites
Australian ticks and the medical problems they can cause
Management of tick bites in Australia
GUIDANCE NOTES
Australian endemic tick-borne diseases
Introduction to ticks, Australian ticks and tick-borne diseases
Lyme disease
Prevention and management of tick bites in Australia
Tick-induced allergies: Tick anaphylaxis and mammalian meat allergy/anaphylaxis, and tick paralysis

The department’s website also includes information on:

- [Support for patients and providers](#), including information and links for support for people with symptoms attributed to tick bites.

- What we are doing about tick-borne diseases, providing details of support for research into ticks and DSCATT in Australia.

b. The adequacy and effectiveness of the ‘debilitating symptom complexes attributed to ticks’ clinical pathway to support patients.

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 DSCATT Clinical Pathway is a tool/pathway to help structure assessments and the management of patients with a wide variety of symptoms.

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. The literature review underpinning the DSCATT clinical pathway is available on the department’s website.

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. Patient stakeholder feedback received during the consultation period was used to inform the finalisation of the pathway. The department received feedback on the DSCATT Clinical Pathway included feedback from the Lyme Disease Association of Australia.

The symptom complexes to which the name DSCATT has been given incorporate a wide range of symptoms. As there is no clear set of symptoms, and no specific tests applicable for DSCATT (as opposed to tick-borne disease which are detectable via tests), it is not possible to collect data on the number of patients suffering DSCATT, or clinical outcomes from use of the DSCATT Clinical Pathway.

c. Current research to advance the management of complex inflammatory diseases.

Some Australians report chronic debilitating symptom complexes which they associate with exposure to indoor mould and biotoxins. These health effects are often referred to as biotoxin-related illnesses. Some complementary and alternative medicine practitioners have labelled this condition and other related symptoms as Chronic Inflammatory Response Syndrome (CIRS). CIRS was also mentioned in that context of biotoxin-related illnesses in the House of Representatives Standing Committee on Health, Aged Care and Sport *Inquiry into Biotoxin-related Illnesses in Australia*.

In response to the *Inquiry into Biotoxin-related Illnesses in Australia*, the Department of Health and Aged Care has undertaken an evidence review and commissioned the development of a 'Biotoxins (indoor damp and mould) Clinical Pathway' (the Biotoxins Clinical Pathway). The Biotoxins Clinical Pathway assists GPs and other health professionals with the diagnosis, treatment and management of patients with biotoxin-related illnesses and is designed specifically for use in Australia. The clinical pathway encourages patient management through a multidisciplinary approach, and was developed in consultation with medical practitioners, patient and consumer groups. The clinical pathway can be accessed on the Department of Health and Aged Care's website at www.health.gov.au/resources/publications/biotoxins-indoor-damp-and-mould-clinical-pathway?language=en.

In addition to the Biotoxins Clinical Pathway, the Environmental Health Standing Committee (enHealth) has developed a fact sheet on the health effects of mould consolidating jurisdictional advice. The fact sheet is endorsed by the Australian Health Protection Committee (AHPC) and is available at www.health.gov.au/resources/publications/enhealth-guidance-potential-health-effects-of-mould-in-the-environment?language=en.

The National Health and Medical Research Council, through a targeted call for research, has funded relevant research on mould-related illnesses. The purpose of this research is to produce evidence that will improve the broader understanding of the origin and pathophysiology of biotoxin-related illnesses, including CIRS.

Attachment A – DSCATT Senate Inquiry recommendations and progress

Senate Community Affairs References Committee Inquiry: Growing Evidence of an Emerging Tick-borne Disease that causes a Lyme-like Illness for many Australian Patients – Final Report

Recommendation	Implementation/monitoring
<p>Recommendation 1</p> <p>The committee recommends that the Australian Government Department of Health engage with stakeholders following the publication of the National Serology Reference Laboratory (NRL) review to discuss the findings of the review and any bearing those may have on testing for Lyme disease in Australia.</p>	<p>Addressed</p> <p>In November 2017, the final report from the NRL was published on the department’s website². Key stakeholders, including patient groups, were consulted on the outcomes of the report. A Questions and Answers document was also produced to support the release of the report.</p>
<p>Recommendation 2</p> <p>The committee recommends that the Australian Government increase funding for research into tick-borne pathogens as a matter of urgency. This funding should include:</p> <ul style="list-style-type: none"> • funding for research on pathogens which may cause infection; • funding for research on whether newly-identified pathogens can cause illness in humans; and • funding for the development of diagnostic tests which can detect infection by any newly-identified pathogens endemic to Australia. 	<p>Addressed</p> <p>The Government has provided almost \$7.5 million in funding for research into tick-borne pathogens - \$4.5 million to the department and \$3 million to the National Health and Medical Research Council.</p> <p>In 2019, the department engaged the Commonwealth Scientific and Industrial Research Organisation (CSIRO) to undertake two projects:</p> <ul style="list-style-type: none"> • A tick survey to better understand which bacteria, viruses and other pathogens are carried by ticks in Australia and their impact on human health; and • A study to analyse samples from DSCATT and tick-bitten patients for possible biomarkers. <p>In December 2021, the department engaged CSIRO to undertake further research on the novel <i>Borrelia</i> species, and to understand the significance of the biomarker findings of the tick biomarker project.</p> <p>Additionally, CSIRO undertook further work to expand its survey of <i>Borrelia</i> in Australian ticks</p>

² Refer: <https://www1.health.gov.au/internet/main/publishing.nsf/Content/ohp-lyme-disease.htm#nrl>

Recommendation	Implementation/monitoring
	<p>and to characterise the Australian <i>Borrelia</i> species. Overall findings from this work indicate Australian <i>Borrelia</i> species are largely restricted to specific wildlife hosts including goannas, snakes, and echidnas, and are not carried by common human-biting tick species. CSIRO also isolated an Australian <i>Borrelia</i> species (<i>B. taylori</i>) for the first time and experimentally demonstrated that this bacterium is not infective to humans.</p> <p>When ready for publication all data and results will be made available through open-access peer-reviewed publication(s) in scientific journals. Due to the nature of the peer-review process, it is difficult to determine the future timing of the final publication(s).</p>
<p>Recommendation 3</p> <p>The committee recommends that government medical authorities, in consultation with stakeholders including the Australian Chronic Infectious and Inflammatory Diseases Society (ACIIDS) and the Karl McManus Foundation, establish a clinical trial of treatment guidelines developed by ACIIDS with the aim of determining a safe treatment protocol for patients with tick-borne illness.</p>	<p>Addressed</p> <p>The DSCATT Clinical Pathway has been developed as the diagnosis and referral pathway tool for 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.</p>
<p>Recommendation 4</p> <p>The committee recommends that the Australian Government allocate funding for research into medically-appropriate treatment of tick-borne disease, and that medical authorities measure the value of treatment in terms of patient recovery and return to health. The best treatment options must then be developed into clinical treatment guidelines.</p>	<p>Addressed</p> <p>The Government has provided over \$8 million in funding for research into tick-borne pathogens, the development of the clinical pathway to support multidisciplinary care, and education materials to assist with general knowledge about ticks and tick-borne diseases.</p>
<p>Recommendation 5</p> <p>The committee recommends that the Australian Government Department of Health facilitate, as a matter of</p>	<p>Addressed</p> <p>The department convened two forums (April and July 2018) to engage with medical professionals, state and territory health authorities and patient</p>

Recommendation	Implementation/monitoring
<p>urgency, a summit to develop a cooperative framework which can accommodate patient and medical needs with the objective of establishing a multidisciplinary approach to addressing tick-borne illness across all jurisdictions.</p>	<p>groups on the concept of multidisciplinary care. From these forums and further consultation with patients and medical providers, an evidence based clinical pathway and multidisciplinary care model was developed.</p> <p>The DSCATT clinical pathway was made available via the department’s website in November 2020 with a supporting literature review published in December 2020.</p> <p>To further support patients and clinicians, a suite of tick education materials was published on the department’s website from November 2022.</p>
<p>Recommendation 6</p> <p>The committee recommends that federal, state and territory health agencies, through the Council of Australian Governments Health Council, develop a consistent, national approach to addressing tick-borne illness.</p>	<p>Addressed</p> <p>The DSCATT clinical pathway was widely supported as a consistent national approach to addressing tick-borne illness. It is supported by a range of educational and awareness materials, published on the department’s website, to assist health professionals and the public to better understand Australian ticks, tick-borne illness in Australia and Lyme disease.</p>
<p>Recommendation 7</p> <p>The committee recommends that the Australian Government Department of Health urgently undertake an epidemiological assessment of the prevalence of suspected tick-borne illness in Australia, the process and findings of which are to be made publicly available.</p>	<p>Addressed</p> <p>The department notes the great difficulty in doing an epidemiological assessment in the absence of a clear cause or causes of symptoms.</p> <p>Should the peer-reviewed results of the CSIRO novel <i>Borrelia</i> and biomarker research project identify a tick-borne disease that matches a symptom complex, the feasibility of an epidemiological study will be examined.</p>
<p>Recommendation 8</p> <p>The committee recommends that the Australian Government Department of Health establish the prevalence and geographical distribution of overseas-acquired Lyme disease in Australia.</p>	<p>Addressed</p> <p>The department recognises that many medical practitioners are not familiar with overseas-acquired Lyme disease and has developed educational materials to inform Australian medical practitioners. For example, A guideline on overseas-acquired Lyme disease has been published on the department³’s website.</p>

³ Refer: <https://www1.health.gov.au/internet/main/publishing.nsf/Content/cda-cdi3904d.htm>

Recommendation	Implementation/monitoring
<p>Recommendation 9</p> <p>The committee recommends that Australian medical authorities and practitioners addressing suspected tick-borne illness:</p> <ul style="list-style-type: none"> consistently adopt a patient-centric approach that focusses on individual patient symptoms, rather than a disease label; and remove 'chronic Lyme disease', 'Lyme-like illness' and similar 'Lyme' phrases from diagnostic discussions. 	<p>Addressed</p> <p>The evidence based and patient centric DSCATT clinical pathway was published on the department's website in November 2020 with a supporting literature review published in December 2020. In January 2021, the department encouraged professional organisations and colleges to promote the clinical pathway to their members.</p> <p>The department has adopted and continues to promote the term DSCATT to refer to suspected tick-borne illness. Clarification on this decision has been provided through position statements available on the department's website.⁴</p>
<p>Recommendation 10</p> <p>The committee recommends that, to help the referral of patients for guided and comprehensive pathology testing, medical practitioners work with pathologists, especially microbiologists, immunologists, chemical pathologists and haematologists to optimise diagnostic testing for each patient.</p>	<p>Addressed</p> <p>To support patients and medical practitioners, the DSCATT clinical pathway was published on the department's website in November 2020 with a supporting literature review published in December 2020. The clinical pathway is an evidence based multidisciplinary tool designed to support clinicians' decision making on differential diagnoses and referral pathways for patients presenting with DSCATT.</p>
<p>Recommendation 11</p> <p>The committee recommends that the Australian Government Department of Health work closely with the Australian Medical Association and Royal Australian College of General Practitioners to ensure that general practitioners have a better understanding of how to treat patients who present with complex symptoms.</p>	<p>Addressed</p> <p>The department will continue to consult and communicate with the Australian Medical Association and the Royal Australian College of General Practitioners on its DSCATT projects.</p> <p>In January 2021, the department advised professional organisations and colleges including the Australian Medical Association and the Royal Australian College of General Practitioners that the clinical pathway had been published and requested that organisations promote its use.</p>

⁴ Refer: <https://www1.health.gov.au/internet/main/publishing.nsf/Content/ohp-lyme-disease.htm>

Recommendation	Implementation/monitoring
<p>Recommendation 12</p> <p>The committee recommends that treatment guidelines developed by Australian medical authorities emphasise the importance of a multidisciplinary approach to patient care, involving consultation between general practitioners and specialists with expertise in neurology, psychiatry, rheumatology, immunology, infectious diseases and microbiology.</p>	<p>Addressed</p> <p>In November 2020 the DSCATT clinical pathway was published on the department's website with a supporting literature review published in December 2020. The clinical pathway is an evidence based multidisciplinary tool designed to support clinicians' decision making on differential diagnoses and referral pathways for patients presenting with DSCATT.</p>