



Australian Government

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

Inquiry into the growing evidence of an emerging tick-borne
disease that causes a Lyme-like illness for many Australian
patients

November 2017

Introduction

The Australian Government has taken an interest in, and is concerned for, Australian patients who are sharing their stories about suffering with debilitating symptom complexes attributed to ticks. The Australian Government Department of Health began engaging with patients and advocacy groups in early 2013 to discuss the concerns about Lyme borreliosis, also known as Lyme disease. Professor Chris Baggoley AO, established a short-term advisory committee (Chief Medical Officer's Advisory Committee on Lyme Disease in March 2013 [CACLD]) to consider the evidence for a *Borrelia* species causing illness in Australians, looking at diagnostic algorithms for borreliosis in Australians and treatments for borreliosis, awareness-raising and education, plus research into borreliosis.

Through regular communication and correspondence, the Government has gained a deeper appreciation and real concern for those Australians experiencing these chronic debilitating symptoms. The Government remains engaged with the patient and medical community to continue to find, share and understand the evidence associated with this medical conundrum. The Government hopes its work with the clinical medicine and research communities will result in answers and relief for patients and their families.

The inquiry into *Growing evidence of an emerging tick-borne disease that causes a Lyme-like illness for many Australian patients* conducted by the Senate Community Affairs References Committee culminated in the Committee's final report (the Report) building on the interim report tabled in May 2016. The Government thanks the Committee and the various stakeholders for their valuable and thoughtful input to the Inquiry.

This response addresses the specific recommendations raised in the Senate Committee's Report, and has been coordinated and prepared by the Department of Health. A general overriding concern of the Government, expressed in these responses, is that, at this time, there is insufficient evidence to conclude that these debilitating symptom complexes are in large part 'tick-borne'. Many of the recommendations pre-suppose a tick-borne aetiology, the acceptance of which may not be in the best interests of achieving appropriate diagnosis and treatment for the suffering of these patients.

The Australian Government through the Department of Health remains open-minded about the cause of the various complexes which manifest as constellations of chronic debilitating symptoms. The best outcome for patients 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 acumen and available diagnostic skills and technology.

Recommendations and Australian Government responses

Recommendation 1

The committee recommends that the Australian Government Department of Health engage with stakeholders following the publication of the National Serology Reference Laboratory review to discuss the findings of the review and any bearing those may have on testing for Lyme disease in Australia.

The Australian Government, through the Department of Health, agrees to share the findings of the report and engage with stakeholders at an appropriate time.

Recommendation 2

The committee recommends that the Australian Government increase funding for research into tick-borne pathogens as a matter of urgency. This funding should include:

- 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.

The Australian Government, through the Department of Health recognises the need to direct funding to determine the cause or causes of the symptoms affecting these patients through research that is comprehensive, evidence-based and incorporates a multidisciplinary assessment.

The department notes the current investigation of potential tick-borne infectious pathogens and the current lack of evidence that the illnesses in question are in large part tick-derived or of an infectious nature. However, the department agrees that research into the microbiome of ticks in Australia is important, given the evidence that ticks can transmit infectious diseases here and in other countries. Evaluation of the potential of identified organisms to cause infections is an important research goal, but will not necessarily lead to the therapeutic answers required by this patient population. It is premature to fund the development of new diagnostic tests unless and until causative agents are identified.

The National Health and Medical Research Council (NHMRC) is the government's lead agency for funding health and medical research. NHMRC accepts, through its various funding schemes, investigator-initiated research proposals in any area relevant to human health. This may include research proposals aimed at debilitating symptom complexes attributed to ticks.

In addition, research into debilitating symptom complexes attributed to ticks will be funded through an NHMRC Targeted Call for Research (TCR). TCRs are one of the mechanisms through which NHMRC directs priority funding to defined areas of need.

The Minister for Health has announced that the NHMRC will hold a TCR on this topic in 2017–2018. As a first step, NHMRC has established a committee of independent scientific experts and consumer representatives to help frame the research question for the TCR. The committee information can be found on the NHMRC website¹.

¹ <https://www.nhmrc.gov.au/grants-funding/apply-funding/targeted-and-urgent-calls-research/research-debilitating>

Funding of \$3 million will be available for this research and will be a significant response to the concerns of patients who are seeking answers to their medical condition.

It is premature to fund the development of new diagnostic tests unless and until causative agents are identified.

Recommendation 3

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.

The department has a working relationship with the Karl McManus Foundation and the Australian Chronic Infectious and Inflammatory Diseases Society and officials have met with representatives of both organisations since the tabling of the final report. Should evidence emerge to define the underlying cause of these debilitating symptom complexes, the department would be happy to engage in discussions about potential treatment trials.

We are cognisant of the evidence of Professor Lindsay Grayson to the Committee, suggesting multiple underlying causes for these symptom complexes. If the government's calls for research into the underlying cause of the symptoms does indicate multiple causes, treatment and treatment trials will need to be tailored to the appropriate diagnoses. Such research may include investigation of the merit of multidisciplinary medical teams in the assessment, diagnosis and treatment of patients.

Recommendation 4

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.

The Australian Government, through the Department of Health recognises the need to direct funding to determine the cause or causes of the symptoms affecting these patients through research that is comprehensive, evidence-based and incorporates a multidisciplinary assessment. Such research may reveal a component of tick-borne disease and contribute to appropriate treatments and the development of treatment guidelines.

Ethically designed clinical trials may be possible in the future when the causes of these debilitating symptom complexes are better understood.

Recommendation 5

The committee recommends that the Australian Government Department of Health facilitate, as a matter of 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.

The Australian Government, through the Department of Health, partially supports this recommendation, and will arrange a forum with the proviso that stakeholders do not meet under the premise that the diseases in question are proven to be tick-borne. The Minister for Health and Minister for Sport, the Hon Greg Hunt MP, will convene and attend the forum. State and territory health authorities, the Australian Medical Association, representatives from the relevant medical colleges, along with patient groups, will be invited and encouraged to participate in the forum. All parties attending the forum will contribute to the development of a framework for patient-centred multidisciplinary care teams.

For the best care, including improving access to care, we believe that these patients need a coordinated multidisciplinary assessment and management approach. The department has already engaged with the learned medical colleges to facilitate this, noting the Commonwealth does not provide direct clinical services. States and territories, through specialist medical practitioners in their public hospitals, are best placed to play a leading role in establishing a multidisciplinary approach to care. Such an approach will also require each patient's general practitioner to be involved, in addition to general and subspecialty physicians, pathologists, psychiatrists and allied health professionals. In 2017, the department will approach state and territory government health authorities to propose a patient-focused plan to pilot a multidisciplinary assessment and management clinic designed to answer research questions in multiple jurisdictions. The pilot program will then guide progress.

Recommendation 6

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.

The Australian Government, through the Department of Health would support consideration of a national approach via the Council of Australian Governments' Health Council (CHC) and the Australian Health Ministers' Advisory Council (AHMAC) to the comprehensive multidisciplinary management of these debilitating symptom complexes. The Government, however, emphasises the need for an open mind on causality, so a national approach would not presuppose a tick-borne aetiology.

Recommendation 7

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.

The Australian Government, through the Department of Health recognises the need to determine the cause or causes of the symptoms affecting these patients through research that is comprehensive, evidence-based and incorporates a multidisciplinary assessment. Should such research reveal an identifiable tick-borne disease that matches a symptom complex, the feasibility of an epidemiological study will be examined.

At this time, it is not possible to undertake such an epidemiological study without the evidence of, or ability to accurately diagnose, uncharacterised tick-borne illnesses (other than identified illnesses in Australia such as Australian Rickettsial infections and mammalian meat allergy).

Recommendation 8

The committee recommends that the Australian Government Department of Health establish the prevalence and geographical distribution of overseas-acquired Lyme disease in Australia.

Collecting epidemiological data on overseas acquired Lyme disease would be best achieved if overseas-acquired Lyme disease was nationally notifiable. Lyme disease has previously been considered by national public health experts twice for inclusion in the Australian National Notifiable Diseases List, however, on both occasions, the criteria for inclusion were not met.

As an alternative to collecting epidemiological data, the Australian Government, through the Department of Health, has published a guideline on overseas-acquired Lyme disease, which is publicly available. The department recognises that many medical practitioners are not familiar with overseas-acquired Lyme disease and will undertake through an education and awareness raising endeavour to inform Australian medical practitioners of the importance of recognising overseas-acquired Lyme disease.

Recommendation 9

The committee recommends that Australian medical authorities and practitioners addressing suspected tick-borne illness:

- 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.

The Australian Government, through the Department of Health, has a patient-centric approach to health care.

The department strongly supports the removal of the terms “Lyme Disease”, “Lyme disease-like Illness” and “Chronic Lyme Disease” from diagnostic discussions. They are unhelpful and divisive.

At present, there is not a clear agreed alternative nomenclature. The term adopted by the Committee “suspected tick-borne disease” is presumptive and could be divisive. The department proposes to use the term “Debilitating Symptom Complexes Attributed to Ticks” (DSCATT) which NHMRC has now adopted to describe its TCR, to describe the heterogeneous nature of the debilitating symptom subgroups with acknowledgement that ticks may have a role.

Recommendation 10

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 hæmatologists to optimise diagnostic testing for each patient.

The Australian Government, through the Department of Health, supports this recommendation.

Recommendation 11

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.

The Australian Government, through the Department of Health, supports this recommendation and will continue to encourage the Australian Medical Association and the Royal Australian College of General Practitioners to raise awareness amongst its members of the need to care for patients presenting with debilitating symptom complexes attributed to ticks sympathetically and with compassion.

Recommendation 12

The committee recommends that treatment guidelines developed by Australian medical authorities emphasise the importance of a multidisciplinary, case conference approach to patient care, involving consultation between general practitioners and specialists with expertise in neurology, psychiatry, rheumatology, immunology, infectious diseases and microbiology.

The Australian Government, through the Department of Health, strongly supports this recommendation and will work with state and territory health agencies under a national approach as proposed in Recommendation 6 of the report.