PARLIAMENTARY INQUIRY QUESTION ON NOTICE

Department of Health and Aged Care

Senate Community Affairs References Committee

Inquiry into access to diagnosis and treatment for people in Australia with tick-borne diseases.

29 January 2025

PDR Number: IQ25-000015

Patient care and DSCATT

Spoken

Hansard page number: 66

Senator: Linda Reynolds

Question:

Senator REYNOLDS: Professor Lum, following on from the chair's question, it does clearly say that the DSCATT is a diagnosis and referral pathway. But can I take a step back from that and say I would implore the department to, not in a defensive way, go through and have a look at what has been said about DSCATT. The overwhelming evidence we've had is that it's designed to be patient centred but it's not working that way, and it is not a diagnosis and treatment tool. I think what the college of GPs have said is actually quite sensible. Could I ask in good faith—not that you wouldn't—that you talk to the department and go away and—perhaps, if we can call them back, we'll ask the department to deal with this in more detail. Would you be happy to take that on notice?
Prof. Lum: Yes

Answer:

The DSCATT Clinical Pathway has been developed as the diagnostic 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.

The development of the document was informed by a detailed Stakeholder Engagement Strategy, which involved forums and written feedback from Government representatives, medical professionals and patient groups.

The DSCATT Clinical Pathway aims to support health professionals based on the patient's medical history and presenting symptoms, and assist general practitioners with evidence-based decision making to clinically manage their patients. The Department of Health and Aged Care understands that there are some stakeholder groups who are dissatisfied with it.

For tickborne infections involving pathogens which have been well characterised, there are useful and robust in vitro diagnostic devices and treatments suitable for the management of infections like overseas-acquired Lyme disease, Q fever, the spotted fevers, and rickettsial infections.

The clinical pathway assists with diagnostic and referral pathways for patients presenting with unresolved debilitating symptoms which cannot be attributed to a readily diagnosable disease. A clinical management guideline is not yet possible for patients with medically unexplainable symptoms which they attribute to ticks, due to the lack of definitive evidence.

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Inquiry into access to diagnosis and treatment for people in Australia with tick-borne diseases.

29 January 2025

PDR Number: IQ25-000017

Better information to GPs to relieve the suffering of thousands of patients

Spoken

Hansard page number: 67

Senator: Linda Reynolds

Question:

Senator REYNOLDS: Dr Lum, I appreciate that analysis and information, but, while all of this research is going on, what distresses me greatly is that, in 2016, we had the inquiry, and there were incredibly sick people—some cases led to suicide—who did have very complex symptoms and hadn't been treated properly. We still have that situation today. You said in this report that there's been $8 million of funding into research—we could only count up to just over $4 million—to produce two reports now: one that will tell us that things can come from ticks, which we knew beforehand, and one about cognitive based assistance for people. But, from the evidence that we've had, there is nothing in all of that and from all of that time that is doing anything. Regardless of whether you have been able to diagnose exactly what pathogen it is, there are people who are sick and who, along with their family, have the most appalling quality of life, and they are not receiving any treatment for a whole variety of reasons.

If you could perhaps take this back for when the department appears, it would be really good to hear about what can be done. The GPs said they don't have enough information to provide that treatment now, so could you come back—and we'll get the department to come back, hopefully, through you, Chair—and answer what we can do now to provide better information to GPs who can relieve the suffering of thousands of patients today, even if you don't know exactly what pathogen it is. I haven't heard anything yet from anybody who's looking at the patients and the people who are suffering today.

Answer:

The Australian Government is committed to supporting patients who are experiencing illness attributed to ticks and the medical practitioners who treat them, as well as investigating novel causes of, and potential new treatments for, tickborne illness in Australia.

Since the 2016 enquiry, approximately $8 million in funding has been allocated for:

- Research into tick-borne pathogens, engaging the Commonwealth Scientific and Industrial Research Organisation (CSIRO).
- Development of the Clinical Pathway to support health professionals' decision making on different diagnosis and referral pathways for patients presenting with unresolved debilitating symptoms.
- Development of a range of education and awareness materials to assist health professionals and the public to better understand tick-borne illnesses in Australia and provide best practice advice regarding tick bite prevention and tick removal.

As noted in the response to IQ25-000015, the DSCATT Clinical Pathway does provide guidance on treatment options for tickborne infections involving pathogens which have been well characterised like overseas-acquired Lyme disease, Q fever, the spotted fevers, and rickettsial infections. However, unfortunately, at this stage there is no clear treatment advice for patients with medically unexplainable symptoms which they attribute to ticks, due to the lack of definitive evidence.

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29 January 2025

PDR Number: IQ25-000018

Multidisciplinary requirements

Spoken

Hansard page number: 52--55

Senator: Maria Kovacic

Question:

Senator KOVACIC: For this particular grant, was there a requirement that it be multidisciplinary? Was that left to the applicants or was it specific that it was a narrow focus? Was this something very much targeted as a focus only on psychotherapy, as an example?

Dr Johnson: It was absolutely not narrowly focused on psychotherapies; it was deliberately broad to cover—as I mentioned in that first aim—physical, social and psychosocial causes. It was deliberately broad to capture all and not make assumptions about this, as our first targeted call in this area. I'd have to take on notice if there was a specific requirement about multidisciplinarity; I can report back to the committee on that. Sometimes we'll have words that encourage that or give some hint to the peer reviewers that this is something we value. Other times it might be a harder rule. I can take that on notice

Answer:

The NHMRC targeted call for research into debilitating symptom complexes attributed to ticks Call-Specific Funding Rules outlined that:

"NHMRC is keen to see collaborative and multidisciplinary research to avoid duplication of effort and to develop synergies between researchers and clinicians looking at different aspects of causes, diagnosis, symptom management and treatment."

More information, including the Call-Specific Funding Rules can be found on GrantConnect (GO ID: GO1293).

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29 January 2025

PDR Number: IQ25-000019

Targeted Calls for Research (TCR) measure of success in terms of reports and outcomes

Spoken

Hansard page number: 54

Senator: Linda Reynolds

Question:

Senator REYNOLDS: I understand funding, but $900 million is a lot of money. I absolutely get and agree that you should not be too narrow and miss new and novel underresearched areas, which this absolutely is. I get that, but how do you measure success for the taxpayer in terms of this TCR, for example? On notice, if you can go back and say: 'With TCR, this is what we defined. This is what success would have looked like in terms of reports and outcomes five years later.' A lot of people in departments and elsewhere in the medical profession say: 'We've got these reviews underway. We won't comment or do anything.' I can tell you they are not going to come up with anything remotely useful. How can we learn from this, and then what would be the process under this TCR? Perhaps in our report we could say that there are these avenues for people who are brave enough. Then if we can get them to come out and say, 'I do want to do this diagnosis study,' how could they do that?

Dr Johnson: It's a very complex area around evaluation of research and how to determine benefit, whether that's through incremental knowledge creation or whether it's actual interventions in a clinic. It's something that we focus on a lot. I don't think we have the full answer to that, but it's something we're looking at

Senator REYNOLDS: Reconfirming that ticks are disgusting, dirty little creatures who have a lot of nasty diseases in them—that's what you funded. Thanks.

CHAIR: I know that you can't give an opinion, Dr Johnson, so we might leave it so that you can provide on notice any information that you can around the measure of success and what measures NHMRC uses, as Senator Reynolds has requested.

Answer:

A successful TCR grant would be one that delivers on the expected outcomes as described in the NHMRC Targeted call for research into debilitating symptom complexes attributed to ticks (DSCATT) Call-Specific Funding Rules. The expected outcomes of the call are:

- The development of evidence based approaches to diagnosing DSCATT, including the development of a clinical case definition.
- A better understanding of the physical, psychological and social aspects of patients' experiences of DSCATT.
- Greater clarity over the role and effectiveness of diagnostics, approaches to symptom management and treatments for DSCATT.

Grant recipients are required to submit an annual progress report and a final report outlining the achievements and progress against the aims of the initiative. Annual progress reports are published on NHMRC's website: https://www.nhmrc.gov.au/funding/targeted-calls-research/debilitating-symptom-complexes-attributed-ticks/annual-progress-reports. As outlined in these annual progress reports, published papers are already available with further information about the studies and preliminary outcomes.