

## Chapter 2

### Experience of patients and access to treatment

2.1 As outlined in Chapter 1, the committee has received over 1000 personal submissions from or on behalf of Australians suffering from chronic debilitating symptoms. The committee is deeply concerned by evidence that many submitters have experienced significant challenges in accessing appropriate healthcare to address their symptoms. In particular the committee is concerned by evidence that suggests submitters have been insulted and humiliated by some medical practitioners when seeking treatment.

2.2 This chapter examines the experience of submitters in accessing treatment, particularly those diagnosed with Lyme-like illness. It examines how the ongoing debate about whether Lyme disease is endemic to Australia contributes to the perceived stigma about diagnoses of Lyme-like illness and impacts on the ability of patients to access treatment. It also examines the treatments prescribed by Lyme-literate practitioners and allegations that these practitioners are unfairly targeted for disciplinary action by medical authorities.

#### Experience of sufferers of chronic debilitating symptoms

2.3 Submitters suffering chronic debilitating symptoms can be divided into four main groups:

- those who acquired and were diagnosed with classical Lyme disease in an endemic area overseas;
- those who acquired their illness overseas but weren't diagnosed;
- those who became ill following a tick or other insect bite in Australia; and
- those who have experienced a long-term chronic illness in Australia and may or may not have been bitten by a tick or other insect.

2.4 The common experiences of patients in these groups are summarised below.

#### *Illness acquired overseas*

2.5 A small number of submitters explained that they acquired their illness overseas. In some cases, patients became ill following a tick bite in an area where classical Lyme disease is endemic.<sup>1</sup> In other cases, patients do not recall a tick bite, but became ill following another kind of bite (such as bed-bugs).<sup>2</sup> A number of submitters do not recall any kind of bite and their symptoms did not manifest until after returning to Australia.<sup>3</sup> The common treatment pathways for these submitters are illustrated in Figure 2.1.

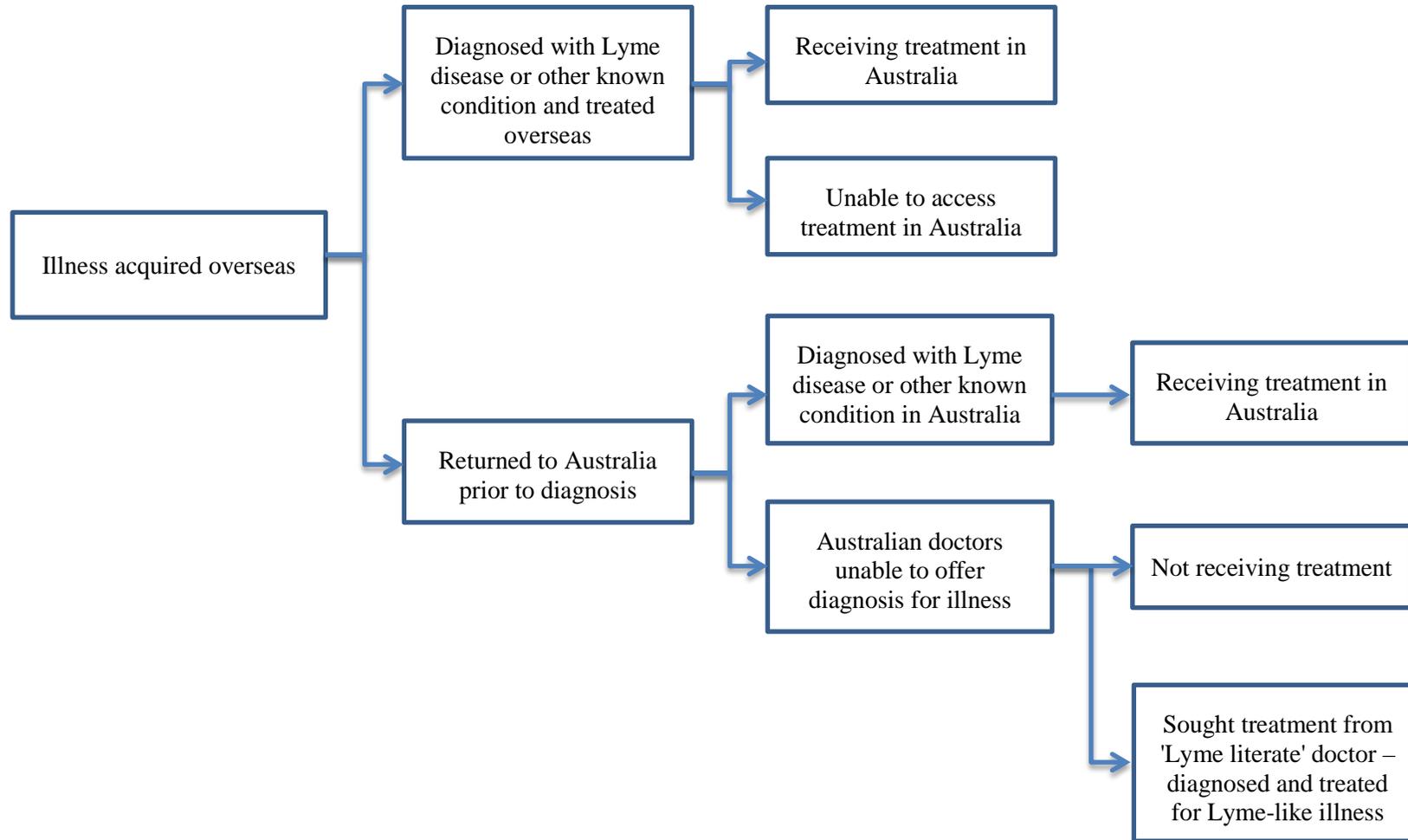
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1 See: *Submission 42; Submission 298.*

2 See: *Submission 123; Submission 287.*

3 See: *Submission 405, Submission 586; Submission 834.*

**Figure 2.1 – Patient treatment pathways –Illness acquired overseas**



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### ***Illness acquired in Australia***

2.6 The majority of submitters stated that they acquired their illness in Australia. In many cases submitters had no history of travel to an endemic area for classical Lyme disease.

#### *Illness following tick bite*

2.7 Some submitters state that they became ill immediately following a tick bite in Australia. Symptoms described by these submitters include a rash around the bite and a range of symptoms including fatigue, arthritis and chronic pain.<sup>4</sup>

2.8 In some cases, submitters were diagnosed with other known tick-borne infections, such as Q fever, Spotted Fever, Rickettsia, Queensland Tick Typhus or allergy to tick toxin, and received treatment.<sup>5</sup>

2.9 However, in most cases, the submitters state that medical practitioners were not able to identify or diagnose the illness, or offer any effective treatment.<sup>6</sup>

#### *Long-term chronic illness*

2.10 The largest group of submitters is those who have experienced a long-term chronic illness. In many cases, these submitters cannot recall being bitten by a tick. In cases where submitters can recall a tick bite, this may have predated the onset of their illness by a number of years.<sup>7</sup>

2.11 Figure 2.2 outlines the treatment pathways for these submitters.

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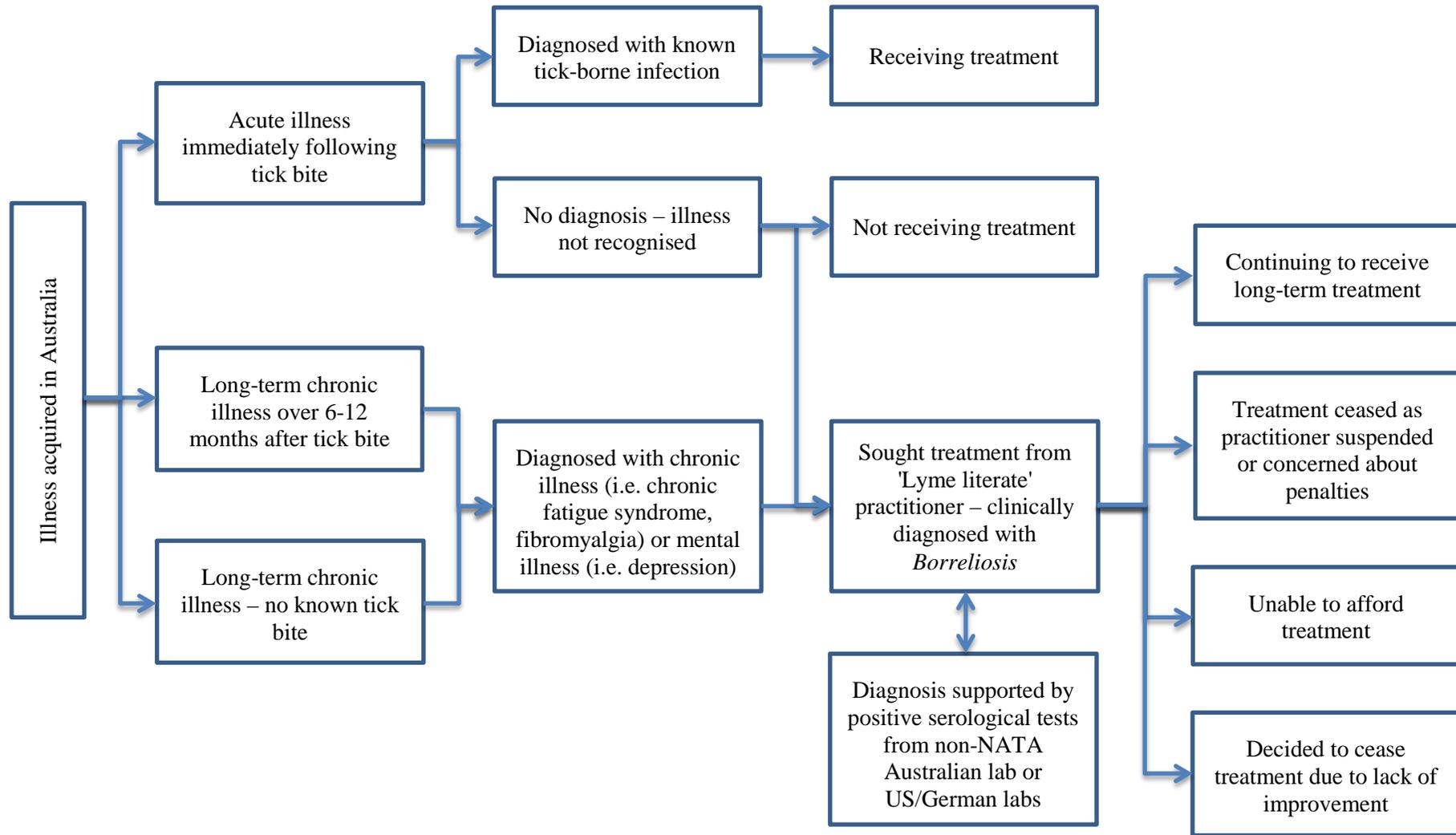
4 See, for example: *Submission 104; Submission 149; Submission 206; Submission 295; Submission 320.*

5 See, for example: *Submission 110; Submission 116; Submission 186.*

6 See, for example: *Submission 19; Mr Paul Fenwick, Submission 27; Ms Christine Linigen, Submission 70; Submission 72; Submission 104; Ms Natalie Young, Submission 140; Submission 142; Submission 143; Submission 149; Submission 163; Submission 169; Submission 198; Submission 206.*

7 See, for example: *Submission 114; Submission 170; Submission 178; Submission 196.*

**Figure 2.2 – Patient treatment pathways from submissions – Illness acquired in Australia**



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## Treatment for patients

2.12 The committee heard that patients diagnosed with chronic debilitating symptoms experience significant difficulties accessing diagnosis and treatment from Australian healthcare services.

### *Illness acquired overseas*

2.13 Submitters who acquired their illness overseas expressed particular concern that Australian medical practitioners may not recognise or effectively diagnose overseas illnesses, such as classical Lyme disease.

2.14 The committee heard that as part of the Chief Medical Officer's Clinical Advisory Council on Lyme Disease, the department has been working with states and territories to raise awareness and assist with the diagnosis of classical Lyme disease through the development of the *Australian guideline on the diagnosis of overseas acquired Lyme disease/borreliosis*. Dr Gary Lum from the Department of Health (department) told the committee:

This guide was developed with the assistance of patient advocates as well as experts in immunology, microbiology and infectious diseases. The guideline was shared with Australian general practitioners, emergency physicians, other relevant specialists as well as the Australian Medical Association.<sup>8</sup>

2.15 However, evidence from some submitters with a history of travel to an area where classical Lyme disease is endemic suggested that some Australian doctors may not be aware of Lyme disease and the appropriate methods for diagnosis and treatment. For example, one submitter noted that he acquired Lyme disease in the United States (US) following a tick bite and was diagnosed and treated by US doctors. Upon returning to Australia, he continued to experience symptoms but struggled to get appropriate treatment:

For me the issue was not so much that the disease was active, it was that doctors were unable to understand the left over side effects that continue to deteriorate my general health and well-being ... I would love to see more education and awareness about Lymes disease here in Australia, particularly around managing the ongoing side-effects.<sup>9</sup>

2.16 Similarly, another submitter who was bitten by a tick in the US expressed frustration at not being treated for Lyme disease in Australia:

People say being diagnosed with cancer is very scary, but try being diagnosed with a potentially fatal disease when there is no help from the medical profession nor support from the Government.

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8 Dr Gary Lum, *Committee Hansard*, Canberra, 20 April 2016, pp 2–3.

9 Name withheld, *Submission 298*, p. 2.

Regardless if the Lyme bacteria is in Australia or not, I was bitten in the USA, so why shouldn't I be treated? People who contact Malaria or tuberculosis overseas can receive treatment in Australia.<sup>10</sup>

2.17 Dr Lum told the committee that despite efforts by the department to educate practitioners, there was a risk that people infected with classical Lyme disease overseas may not be appropriately treated in Australia:

We recognise that people infected overseas who return to Australia have a risk that their classical Lyme disease will not be recognised or appropriately treated, in spite of our regular advice to Australia's doctors to pay attention to this situation.<sup>11</sup>

2.18 Dr Lum noted that the department was committed to education and awareness raising of classical Lyme disease, but acknowledged it could do more to communicate with the medical profession:

What the department has been trying to do is communicate with the medical profession. If, as part of the Senate inquiry and as part of the recommendation, we could possibly do more to communicate with the medical profession on this, we certainly would.<sup>12</sup>

### ***Illness acquired in Australia***

2.19 More commonly, submitters have acquired their illness in Australia, but have not been able to be readily diagnosed and treated by Australian medical practitioners.

2.20 As discussed in Chapter 1, many of these submitters have been diagnosed with Lyme disease or Lyme-like illness by 'Lyme literate' practitioners. However, due to the significant debate in Australia about the existence of Lyme disease, these submitters noted that they have experienced significant challenges in accessing treatment in Australia.

### ***The Lyme disease debate in Australia***

2.21 The existence of Lyme disease in Australia is highly controversial and has attracted significant media attention and public debate. This debate relates to two closely related questions:

- whether the causative agent for classical Lyme disease (either known *Borrelia* species such as *B. burgdorferi* or an as yet unidentified *Borrelia* species) is endemic to Australia (i.e. has been identified in Australia); and
- consistent with the international debate about 'chronic' Lyme disease, whether the chronic debilitating symptoms experienced by Australian patients are caused by an ongoing active infection of *Borrelia* and associated co-infections, or another as yet unidentified underlying cause or causes.

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10 See: Name withheld, *Submission 519*, pp 2–3.

11 Dr Gary Lum, *Committee Hansard*, Canberra, 20 April 2016, p. 2.

12 Dr Gary Lum, *Committee Hansard*, Canberra, 20 April 2016, p. 13.

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*Is classical Lyme disease endemic to Australia?*

2.22 The position of Australian Commonwealth, state and territory governments and medical authorities is that the causative agent for classical Lyme disease is not endemic to Australia.<sup>13</sup> In their submissions to the inquiry, these authorities state that there is no evidence to suggest that *B. burgdorferi* or any other *Borrelia* species known to cause Lyme disease have been identified in Australian ticks or patients.<sup>14</sup> In his 2014 progress report on Lyme disease in Australia, the Chief Medical Officer (CMO), Professor Chris Baggoley, stated that there is no evidence that the bacteria causing Lyme disease are endemic to Australia:

There is still no routine finding of *Borrelia* spp in ticks in Australia.

The conclusive finding of a bacterium that could cause Lyme disease-like syndrome in Australia has yet to be made. Such a finding would put beyond doubt the existence of Lyme disease, or a Lyme disease-like syndrome in Australia.<sup>15</sup>

2.23 Most submissions from medical authorities<sup>16</sup> support the Royal College of Pathologists Australasia (RCPA) position paper on diagnostic testing for Lyme disease in Australia that states that:

Only a genuine case in a non-travelling Australian patient would confirm the disease as being present in Australia.<sup>17</sup>

2.24 The CMO has stated that other 'vectors and routes of transmission are postulated, but yet to be demonstrated'.<sup>18</sup> In evidence to the committee, Dr Gary Lum noted that there may be a range of possible causes for Lyme-like illness:

In the context of evolving Australian research data, we need to consider that the cause may not be limited to a single bacterial species. Parasitic and viral causes, as well as environmental toxins, should also be considered for investigation, as well as other potential medical explanations.<sup>19</sup>

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13 See, for example: Department of Health, *Submission 495*; Western Australian Department of Health, *Submission 529*; Victorian Department of Health and Human Services (DHHS), *Submission 547*; Royal College of Pathologists of Australasia, *Submission 532*.

14 *Submission 495*, p. 2.

15 Professor Chris Baggoley, Progress Report on Lyme Disease in Australia, 31 July 2014, <http://www.health.gov.au/lyme-disease> (accessed 3 May 2016).

16 See: Communicable Diseases Network Australia (CDNA), *Submission 531*; Royal Australasian College of Physicians, *Submission 754*; Australian Society for Microbiology, *Submission 781*; NSW Health, *Submission 457*; Victorian DHHS, *Submission 547*.

17 RCPA, *Position statement: Diagnostic Laboratory testing for Borreliosis ('Lyme Disease' or similar syndromes) in Australia and New Zealand*, February 2014, <http://www.rcpa.edu.au/Library/College-Policies/Position-Statements/Diagnostic-Laboratory-testing-for-Borreliosis-Lyme> (accessed 7 December 2015).

18 Professor Chris Baggoley, Progress Report on Lyme Disease in Australia, 31 July 2014, <http://www.health.gov.au/lyme-disease> (accessed 3 May 2016).

19 Dr Gary Lum, *Committee Hansard*, Canberra, 20 April 2016, p. 2.

2.25 The first Australian cases of a syndrome consistent with Lyme disease were reported in the Hunter Valley region of NSW in 1982. Further clinical cases were reported on the NSW south and central coast in 1986, and in Queensland between 1986 and 1989.<sup>20</sup> Since these cases, there have been a number of studies examining whether locally acquired Lyme disease exists in Australia. According to a recent paper summarising research into Lyme disease in Australia, these studies have found no conclusive evidence that indicates the presence of the causative agent for Lyme Disease—*Borrelia burgdorferi*—in Australia and 'the diagnoses of [Australian] Lyme Borreliosis ... have been primarily by clinical presentation and laboratory results of tentative reliability and the true cause of these illnesses remains unknown'.<sup>21</sup>

2.26 However, patient advocacy groups and some medical practitioners challenge this position and state that *Borrelia* bacteria known to cause Lyme disease are endemic to Australia. These groups argue that Lyme disease is a 'hidden epidemic' in Australia. They are concerned that there have been a number of cases reported in the media of Australians who have been diagnosed with Lyme disease acquired in Australia, but that these patients have been 'ignored' by the Australian health care system.<sup>22</sup>

2.27 In its submission, the Lyme Disease Association of Australia (LDAA) suggests that evidence over the past fifty years that has demonstrated the existence of an endemic species of *Borrelia* known to cause Lyme disease in Australia has been 'systematically ignored' by medical authorities:

The presence of *Borrelia*, the causative agent of Lyme disease, was established in Australian fauna in 1959 and human cases of Lyme disease

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- 20 R.C. Russell et al, 'Lyme disease: a search for a causative agent in ticks in south-eastern Australia', *Epidemiology and Infections*, v. 122, n. 2, 1994, p. 376, <https://www.jstor.org/stable/3864539> (accessed 11 January 2015).
- 21 Paper provided to the committee by Professor John Mackenzie: Melissa Judith Chalada, John Stenos, Richard Stewart Bradbury, 'Is there a Lyme-like disease in Australia', *One Health*, 2016, Volume 2, pp 42–54, <http://www.sciencedirect.com/science/article/pii/S2352771416300039> (accessed 20 April 2016).
- 22 See, for example: 'The brutal bite of a hidden illness in Australia', *Sunday Times Magazine* (WA), 18 April 2016, <http://www.perthnow.com.au/news/western-australia/stm/the-brutal-bite-of-a-hidden-illness-in-australia--lyme-disease/news-story/7eff05d29199ba092742fd5ff9f23266> (accessed 29 April 2016); 'Lyme disease: Australians "being treated worse than a dog riddled with mange"', *ABC Online*, 12 January 2015, <http://www.abc.net.au/news/2016-01-11/lyme-disease-treatment-in-australia-criticised-by-john-madigan/7080708> (accessed 18 January 2015), 'Canberra family ticked off about lack of recognition of Lyme disease', *Canberra Times*, 24 December 2015, <http://www.canberratimes.com.au/act-news/canberra-family-ticked-off-about-lack-of-recognition-of-lyme-disease-20151217-glpovr.html> (accessed 5 January 2015); 'Lyme disease from tick bite but the doctors say it doesn't exist', *Courier Mail*, 15 November 2015 (accessed 5 January 2015); 'Lyme disease: Federal MP calls for greater recognition of tick-borne illness affecting "thousands"', *ABC Online*, 22 August 2015, <http://www.abc.net.au/news/2015-08-20/federal-parliament-calls-for-lyme-disease-recognition/6710810> (accessed 5 January 2015).

have been reported since the early eighties. Australian authorities ignore this evidence.<sup>23</sup>

2.28 These groups highlight recent studies by Dr Peter Mayne, a retired NSW medical practitioner, that suggest infection from *B. burgdorferi* has been acquired in Australia by one patient and can be transmitted by Australian ticks.<sup>24</sup> However, the Communicable Diseases Network Australia has highlighted that the absence of a published method to facilitate the replication of this finding undermines its significance.<sup>25</sup>

2.29 Other groups, such as the Karl McManus Foundation, a charity that raises funding for tick-borne disease research at the University of Sydney, assert that the causative agent in Australia is not the same as classical Lyme disease overseas, but an indigenous, Australian species of *Borrelia*:

...we do not have *Borrelia burgdorferi*, or Lyme disease, in Australia. What we have is a unique *Borrelia* infection.<sup>26</sup>

2.30 The diagnostic procedures for testing for *Borrelia* bacteria in Australia are examined in detail in **Chapter 3**.

*Is an ongoing infection of Borrelia bacteria responsible for chronic debilitating symptoms in Australian patients?*

2.31 As noted in Chapter 1, the committee has heard that Australian governments and medical authorities do not agree that the chronic debilitating symptoms described by Australian patients are caused by an ongoing *Borrelia* infection. These authorities assert that there is no evidence that the *Borrelia* bacteria that cause Lyme disease are endemic to Australia and suggest that there may be another as yet unidentified underlying cause or causes.<sup>27</sup>

2.32 For example, Professor Stephen Graves from the RCPA told the committee that there is 'clearly something in Australian ticks, or some species of Australian ticks, that is making some Australians sick',<sup>28</sup> but it is unlikely to be caused by *Borrelia*:

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23 Lyme Disease Association of Australia (LDAA), *Submission 528*, p. 6.

24 See: Peter Mayne, 'Emerging incidence of Lyme borreliosis, babesiosis, bartonellosis, and granulocytic ehrlichiosis in Australia', *International Journal of General Medicine*, v. 4, 2011, pp 850–851, [https://www.dovepress.com/articles.php?article\\_id=19731](https://www.dovepress.com/articles.php?article_id=19731) (accessed 7 January 2015); Peter Mayne et al, 'Evidence for Ixodes holocyclus (Acarina: Ixodidae) as a Vector for Human Lyme Borreliosis Infection in Australia', *Journal of Insect Science*, v. 14, 2014, p. 3, <http://jinsectscience.oxfordjournals.org/content/14/1/271> (accessed 7 January 2015).

25 Communicable Diseases Network Australia (CDNA), *Submission 531*, pp 5–6.

26 Dr Mualla McManus, *Committee Hansard*, Brisbane, 15 April 2016, p. 28.

27 See, for example: Australian Medical Association (AMA), *Submission 456*; Australian Society for Microbiology, *Submission 781*; Australian Rickettsial Reference Laboratory Foundation, *Submission 459*; CDNA, *Submission 531*.

28 Professor Stephen Graves, *Committee Hansard*, Brisbane, 15 April 2016, p. 45.

I actually do not think what we are talking about is the *Borrelia* infection. It is not classic Lyme disease. It is not a *Borrelia* infection, although I am keeping an open mind on that possibility—but I do not think it is. What is it?<sup>29</sup>

2.33 Dr Margaret Hardy, a research fellow at the University of Queensland's Institute for Molecular Bioscience, told the committee that due to Australia's geographic isolation, unique species of ticks and host animals, it is unlikely that a *Borrelia* species similar to the *Borrelia* bacteria found in North America and Europe would also be found in Australia:

America and Europe are much more geographically close as well, so it would make sense that if you had two co-evolving types of *Borrelia* you would see them across that close geographic range rather than coming all the way up from there, missing Africa and Asia entirely, and popping up over in Australia.<sup>30</sup>

2.34 Whereas Australian medical authorities suggest that the cause of the chronic debilitating symptoms described by patients is not yet known, patient advocacy groups assert that the cause is infection with *Borrelia*, together with a range of other bacterial co-infections.<sup>31</sup> These groups highlight that chronic *Borrelia* infection is just one of many co-infections that are transmitted to humans by ticks and responsible for causing chronic debilitating illness. For example, the LDAA submitted:

Emerging international research shows that Lyme disease is rarely ever found in isolation of other pathogens; our research supports that ... Typically these are referred to as co-infections, but they are individual and sometimes life threatening infections in their own right. As well as *Borrelia*, an infection from each of those pathogens increases the complexity in the type of symptoms patients actually endure.<sup>32</sup>

### ***Tick-borne illnesses in Australia***

2.35 The committee heard that due to the debate about Lyme disease, some medical practitioners have limited awareness of other possible tick-borne illnesses. A number of submitters reported that on presenting to their GP with tick bites they were not offered any specific treatments and were told that there are no tick borne illnesses in Australia. For example, Ms Linda Ebden told the committee in Perth about her consultation with her GP:

I was covered in tick bites. He said to me: 'You have an allergy. Go home and take some Phenergan.' I said to him, 'Is it possible that it is something from the ticks?' He said, 'No, we do not have tick bite diseases in Australia.'

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29 Professor Stephen Graves, *Committee Hansard*, Brisbane, 15 April 2016, p. 46.

30 Dr Margaret Hardy, *Committee Hansard*, Brisbane, 15 April 2016, p. 39.

31 LDAA, *Submission 528*, pp 57–58.

32 *Submission 528*, p. 58.

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So I never learnt to protect myself. I thought being bitten by ticks was just part and parcel of living in the hills.<sup>33</sup>

2.36 Ms Natalie Young, a National Parks Officer in NSW, noted in her submission that she experienced over 300 tick bites over the course of her career. As a result she suffered a range of debilitating symptoms including headaches, fever, migratory pains and anxiety. Ms Young noted:

Doctor after doctor refused to acknowledge my large number of tick bites as a causation of my illness even though I had had over 300 tick bites at work over seven years. Local GP's were at a loss to explain my illness. After I saw approximately ten local GP's, the referral process started to specialists of varying fields. GP's were considering diagnoses of Chronic Fatigue Syndrome, Tennis Elbow, Lupus, post-viral infections to Barmah and Ross River Fever but as my disease severity worsened, they ruled these out.<sup>34</sup>

2.37 Whereas the committee acknowledges that there is significant debate about whether or not *Borrelia* bacteria known to cause Lyme disease are endemic to Australia, evidence to the committee suggests that both patient advocacy groups and some medical authorities agree that there are likely to be other pathogens in Australian ticks making people sick. Professor Peter Collignon told the committee:

Ticks can cause lots of diseases, not only in Australia but overseas. I think there are probably lots of organisms in ticks—bacteria and even viruses—that we do not know of yet, so I think we have to keep an open mind about what diseases may be transmitted by ticks and what therapy is available or should be used for them.<sup>35</sup>

2.38 According to the department, there are 70 species of hard and soft ticks in Australia, of which 16 species of hard ticks have been reported to bite humans. The Paralysis Tick (*Ixodes holocyclus*) is understood to be responsible for 95 per cent of tick bites in Eastern Australia.<sup>36</sup> In Western Australia, a completely different species of tick, the ornate kangaroo tick (*Amblyomma triguttatum*), is responsible for most tick bites in humans.<sup>37</sup>

2.39 Ticks are hosts and vectors of a number of parasites, bacteria and viruses. The main organisms that may be transmitted by ticks and associated with disease known in Australia are outlined below:

- **Anaplasma** – causes disease in cattle (bovine anaplasmosis, or 'bovine tick fever') and dogs (canine anaplasmosis);

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33 Ms Linda Ebdon, *Committee Hansard*, Perth, 14 April 2016, p. 24.

34 Ms Natalie Young, *Submission 140*, p. 4.

35 Professor Peter Collignon, *Committee Hansard*, Perth, 14 April 2016, p. 31.

36 Department of Health, Preventing and treating tick bites, October 2015, <http://www.health.gov.au/lyme-disease> (accessed 20 November 2015).

37 Professor Stephen Graves, *Committee Hansard*, Brisbane, 15 April 2016, p. 45.

- **Babesia** – a significant cause of disease in cattle (Bovine babesiosis) and dogs (Canine babesiosis);<sup>38</sup>
- **Bartonella** – causes disease in domestic and wild animals including cats and kangaroos – uncertain whether it can cause human disease;
- **Ehrlichia** – causes disease in dogs worldwide but has not been recognised in Australia;
- **Francisella** – relatively rare and no evidence to suggest pathogenic for humans;
- **Rickettsia** – causes several diseases in humans including Queensland tick typhus (*Rickettsia australis*), Flinders Island spotted fever (*Rickettsia honei*), variation of spotted fever (*R. marmionii*) and Q fever (*Coxiella burnetii* – rarely tick-borne).<sup>39</sup>

2.40 The incidence of these tick-borne illnesses and their effects on humans are not clearly known. A number of groups, including the RCPA, suggest that further research needs to be undertaken into these other tick-borne diseases and their impacts on humans. Professor Stephen Graves told the committee:

Let us say it is bacteria, for argument's sake. Which one is it? Or is it more than one? We cannot tell because we do not have the assays to detect those bacteria or the antibodies produced in response to those bacteria in the patients, because those assays have not been developed. That research has not been done, and that is because the money has not been made available to do it. Sorry to come back to money, but that is really what it takes ... Someone has to look at *Babesia* and other protozoa that might be responsible, and somebody has to look at viruses. In other parts of the world, there are many viruses that are tick transmitted and cause very nasty diseases. And we do not have one in Australia? Well, I cannot believe that. I cannot believe that, senators. There have to be some viral tick-transmitted infections in Australia; it is just that we do not know what they are.<sup>40</sup>

2.41 Both patient advocacy groups and medical authorities highlighted that more research is needed into a range of key areas including identifying possible pathogens in ticks and other vectors and clinical studies of patients. These opportunities for research are examined in detail in **Chapter 4**.

2.42 A number of submitters and witnesses highlighted the need for better education and awareness about preventing tick bites to avoid any potential illnesses. Professor Peter Collignon told the committee:

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38 The first reported case of human babesiosis acquired in Australia was published in 2012. See: Sanjaya Senanayake et al, 'First report of human babesiosis in Australia', *Medical Journal of Australia*, v. 196, 2012, pp 350–352. See: Professor Peter Collignon, *Submission 458*, Attachment B.

39 Mackenzie, *Scoping study*, pp 17–19.

40 Professor Stephen Graves, *Committee Hansard*, Brisbane, 15 April 2016, p. 46.

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We should avoid people being bitten by ticks. Ticks are bad for lots of reasons, the same as mosquitos are really bad for people with, in Australia, Ross River virus, Barmah Forest virus and a lot of things. So the two insects that I think we should avoid being bitten by are ticks and mosquitoes. I think we need to have a program to say what to do and, particularly, how you remove a tick without causing more damage by squirting more toxins or whatever into the person. So, yes, I think we need a tick education program.<sup>41</sup>

2.43 The department noted in its submission that it is committed to education and awareness raising about the prevention of tick bites and has produced a publicly available information sheet on tick bites:<sup>42</sup>

In an effort to prevent tick-borne bites [sic] and raise awareness of tick bite first aid, we collaborated with the National Arbovirus and Malaria Advisory Committee as well as with states and territories on a tick bite prevention document for public distribution. It is hoped in future we will incorporate emerging research into tick bite associated mammalian meat allergy and newer techniques for tick removal. The department is committed to such education and awareness raising.<sup>43</sup>

***Committee view***

2.44 The committee acknowledges that there is a debate about whether or not Lyme disease is endemic to Australia. The committee notes the position of the Chief Medical Officer that Lyme disease is not endemic to Australia as the species of *Borrelia* bacteria responsible for causing the disease have not been identified in Australia. The committee also notes evidence from Dr Gary Lum that acknowledges that there may be another causative agent or agents for the chronic debilitating illness described by patients.

2.45 The committee acknowledges that there may be illnesses transmitted by ticks and potentially other vectors that warrant further research. The committee notes that this issue needs further inquiry.

2.46 The committee recognises that more could be done to educate the public and medical professionals about the risk of tick bites and tick-related illnesses in Australia, as well as classical Lyme disease acquired overseas.

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41 Professor Peter Collignon, *Committee Hansard*, Perth, 14 April 2016, pp 34–35.

42 See: *Submission 495*, Attachment I. In his 2015 progress report on the Clinical Advisory Committee on Lyme Disease (CACLD), sent to the President of the Australian Medical Association and presidents of relevant medical colleges, the Chief Medical Officer advised that this prevention document was being prepared and would be available from the department's website. See: *Submission 495*, Attachment J.

43 Dr Gary Lum, *Committee Hansard*, Canberra, 20 April 2016, pp 2–3.

### **Treatment for patients diagnosed with Lyme-like illness**

2.47 Patient advocacy groups argue that because Lyme disease is not recognised as being endemic to Australia, patients seeking treatment experience significant challenges accessing treatment.<sup>44</sup> These difficulties include:

- denial that someone is ill and denial of care;
- stigma and humiliation associated with Lyme-like illness from some medical services;
- accessibility and costs of treatments prescribed by 'Lyme literate practitioners'; and
- limitations placed on 'Lyme literate' practitioners by medical authorities.

### ***Stigma and Lyme-like illness***

2.48 Submitters expressed concern that because Lyme-like illness is not recognised in Australia, patients experience significant stigma when seeking treatment from some medical practitioners. These submitters note that medical practitioners dismiss Lyme disease as a possible diagnosis, arguing that Australia is not an endemic area and therefore Lyme disease does not exist here.<sup>45</sup>

2.49 The committee notes that a large proportion of submitters to the inquiry requested to have their submissions marked as either name withheld or confidential to avoid any possible negative repercussions from their family, friends, employers and medical practitioners.

2.50 One submitter described the treatment her 29 year old daughter had received from medical professionals when she presented with Lyme-like illness:

The worst part of having this illness is the treatment and discrimination that she has received by the majority of the medical profession. She always had to justify why she was there and try to get them to understand that she has pain, but after [a] brief discussion she would be told that there is nothing medically wrong with her and her illness doesn't exist and that stress is causing it all.<sup>46</sup>

2.51 Similarly, Ms Emily O'Sullivan, writing on behalf of her sister Amy, who has been suffering chronic debilitating symptoms for 10 years and has been diagnosed with Lyme-like illness, submitted that:

The Australian medical community not only fails to recognise the disease but seem to have a proactive aversion to accepting Lyme Disease as a possible diagnosis. This has left Amy in an unnerving cycle of denied care. If she claimed to have Lyme Disease in GP clinics and ... hospitals (even

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44 See, for example: LDAA, *Submission 528*; Lyme Australia Recognition and Awareness; and Global Lyme and Invisible Illness Organisation Inc, *Submission 822*; ME/CFS and Lyme Association of WA, *Submission 802*.

45 See, for example: *Submission 1085*; *Submission 571*; *Submission 948*; *Submission 164*.

46 Name Withheld, *Submission 82*, p. [1].

with positive blood tests), she was deemed 'crazy or looking for drugs' and didn't receive care because 'Lyme Disease doesn't exist in Australia'.<sup>47</sup>

2.52 The committee heard from a number of organisations representing patients that indicated that patients are not treated with respect and care by some medical practitioners. The LDAA noted in its submission that it receives:

... constant updates from Australians about how terribly they are treated by the medical profession if they mention that they suspect or have Lyme disease. Patient's [sic] routinely report poor treatment by Australian GPs, infectious disease specialists and other hospital and specialist staff.<sup>48</sup>

2.53 The LDAA notes that the name 'Lyme disease' has attracted such a stigma that 'many patients routinely advise others not to mention the disease at all when reporting their medical history'.<sup>49</sup>

2.54 The committee is particularly concerned by evidence that suggests some patients are humiliated or insulted by medical practitioners for seeking tests or treatments for Lyme-like illness.<sup>50</sup> The Australian Chronic Infectious and Inflammatory Disease Society (ACIIDS), representing 'Lyme literate' practitioners, indicated that many patients have been traumatised by some medical practitioners:

Discrimination against patients suffering from this illness, and the doctors who treat them, is rife. Many patients have been traumatised by their experience with medical specialists and in hospital emergency departments; they have been subject to derision and verbal abuse.<sup>51</sup>

2.55 For example, one submitter described how their neurologist ridiculed them when they brought up Lyme disease:

[My neurologist] spent a whole appointment ridiculing me and asking me why I 'thought I had Lyme'. Repeating 'Lyme Disease is not in Australia' [and] 'It can't be Lyme Disease, we don't have Lyme in Australia' [and] 'Show me proof it's here'[,]

I mentioned the paper that had just been realised [sic] from Curtin [sic] University. This was found to have *Borrelia* on our native Fauna.

'That's on animals' he says.

So I leave another appointment in tears, frustrated and going nowhere.<sup>52</sup>

2.56 One submitter, the father of a child with Lyme-like illness, said that over three years of seeking treatment for his daughter the family faced a series of refusals to treat and abuse by medical practitioners. During an appointment with one neurologist, the

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47 Ms Emily O'Sullivan, *Submission 15*, p. [2].

48 Lyme Disease Association of Australia, *Submission 528*, p. 19.

49 Lyme Disease Association of Australia, *Submission 528*, p. 19.

50 See: *Submission 12*; *Submission 447*.

51 ACIIDS, *Submission 370*, p. 5.

52 Name Withheld, *Submission 296*, p. [3].

family was subjected to a 'highly abusive, emotional and irrational' outburst that included accusing the child of feigning the symptoms and 'personal insults and attacks on the character' of the child and their parents that 'deeply traumatised' the family.<sup>53</sup>

2.57 'Lyme literate' practitioners, such as Dr Richard Schloeffel, suggest that the treatment of patients with Lyme-like illness by some medical practitioners amounts to malpractice:

I cannot talk for other doctors and their thought processes, but I would like to say to every doctor in Australia, 'Wake up to yourselves. Start listening that we've got a real illness. Let's have a proper conversation. Let's do the proper science. Let's fund it ... But we have to put money into it, we have to have a proper conversation and the denialism has to stop, because that is actually malpractice. It is actually negligence on the part of the medical profession.'<sup>54</sup>

2.58 Some medical authorities do not accept that there is any particular stigma associated with Lyme disease or Lyme-like illness. For example, the Australian Rickettsial Reference Laboratory submitted:

We do not accept that there is any more stigma associated with "Lyme-like illness" than there is to many other medical conditions from which many Australian patients already also suffer. Stigma, where it exists, can be broken down by community education over time.

"Stigma" may be in the mind of the beholder. Some patients may perceive that they are being stigmatised, but are probably not. Their doctor is simply trying to obtain a diagnosis of their condition and trying to treat the patient with the best of intentions and based on the current state of medical knowledge. There are many patients who have an illness that has not been currently diagnosed and for which there may be no recognised treatment. Patients with "Lyme-like illness" are not the only patients in this unfortunate position.<sup>55</sup>

2.59 Medical authorities noted that just because there is no evidence that Lyme disease is endemic to Australia, it does not mean that doctors don't care about the welfare of patients. Professor Samuel Zagarella told the committee:

When doctors say that Lyme disease does not exist in Australia I think that a lot of people misinterpret that as being non-caring. The question is whether these people are suffering from Lyme disease [or] a different disease. We believe that at the moment there is no evidence to say that they are suffering from Lyme disease caused by ticks, and caused by *Borrelia burgdorferi* specifically. These people may be suffering from other conditions. There are a lot of non-specific symptoms that these people suffer from, such as arthritis, arthralgia, weakness, lethargy, pain and

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53 Mr Carl Jackson, *Submission 416*, pp [3-4].

54 Dr Richard Schloeffel, *Committee Hansard*, Brisbane, 15 April 2016, p. 24.

55 *Submission 459*, p. 2.

depression. They certainly have some issues, but there is no evidence that Lyme disease as such exists in Australia.<sup>56</sup>

### *Measures to reduce stigma*

2.60 Some witnesses suggested that the stigma experienced by patients could be reduced by avoiding use of the names 'Lyme disease' or 'Lyme-like illness'. As noted in Chapter 1, submitters reported that they do not care what their illness is called; they just want to be able to access treatment.

2.61 One alternative name suggested by Dr Lance Sanders is Hunter Valley disease (HVD), in reference to the first documented case of a Lyme-like illness reported in the Hunter Valley in the 1980s. Dr Sanders noted that this broad term does not assume that the cause or causes for the symptoms have been identified.<sup>57</sup>

2.62 In the United Kingdom, the name 'chronic arthropod-borne neuropathy' is suggested by Dr Matthew Dryden to describe the range of symptoms experienced by patients similar to those in Australia.<sup>58</sup>

2.63 Other possible names for the condition are advocated for by 'Lyme literate' practitioners who argue that the symptoms are caused by *Borreliosis* and a range of co-infections, such as US physician Dr Richard Horowitz.<sup>59</sup> The name Multiple Systemic Infectious Disease Syndrome (MSIDS) is already used by some patient advocacy groups in Western Australia in an attempt to move away from the association with Lyme disease.<sup>60</sup>

2.64 Dr Lum told the committee that the department would support moving away from the 'Lyme' label to better describe the 'chronic debilitating illness that manifests as a constellation of chronic debilitating symptoms' described by submitters:

We are well aware from the patient community and from various members of the medical profession that moving right away from the notion of Lyme disease and Lyme-disease-like illness is probably a very good move.

The problem that we have in Australia in terms of how we work with patients, advocacy groups and the medical profession is that this is not unique to Australia. The issue of a chronic Lyme disease is very contentious and very controversial to the extent that we would like to steer away from that. That is why in the work that we have been doing we have

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56 Professor Samuel Zagarella, *Committee Hansard*, Perth, 14 April 2016, p. 31.

57 Dr Lance Sanders, *Submission 452*, p. 4.

58 Dr Gary Lum, Department of Health, *Committee Hansard*, 20 April 2016, p. 5. See: Matthew Dryden *et al*, 'Lyme borreliosis in southern United Kingdom and a case for a new syndrome, chronic arthropod-borne neuropathy', *Epidemiology and Infection*, v. 143, n. 3, February 2015, pp 561–572, <http://dx.doi.org/10.1017/S0950268814001071> (accessed 23 April 2016).

59 Dr Richard Horowitz uses the name Multiple Systemic Infectious Disease Syndrome to represent 'sixteen potential overlapping medical problems contributing to persistent symptoms in the Lyme patient'. Dr Horowitz reports to have seen over 12,000 chronically ill patients from around the world, including Australia. See: Dr Richard Horowitz, *Submission 936*, pp 1–2.

60 See: Ms Kate Daniels, *Committee Hansard*, Perth, 15 April 2016, p. 13.

tried to distinguish it by describing a chronic debilitating illness that manifests as a constellation of chronic debilitating symptoms. That is a mouthful and I would not propose that as a name. What I am trying to suggest though is that getting away from that name is probably a very good move.<sup>61</sup>

2.65 Another measure to reduce stigma recommended by patients and advocacy groups is formal recognition by Australian medical authorities of Lyme-like illness.<sup>62</sup> At its Brisbane hearing, the committee was presented with a 'Time to Recognise Lyme' clock by Ms Karen Smith and Mr Matt Chant.<sup>63</sup> Mr Chant told the committee:

The time to recognise Lyme clock is a call to action to show that acknowledgement and treatment can help restore hope and health, that the denial of Lyme and other vector borne diseases in Australia is causing devastation and the loss of years of people's lives, and, in far too many instances, their death.<sup>64</sup>

2.66 However, as noted in Chapter 1, Australian medical authorities do not recognise Lyme-like illness as a defined condition, noting that it may be used to describe a 'constellation of debilitating symptoms'.<sup>65</sup>

#### ***Committee view***

2.67 The committee is concerned by the treatment of patients diagnosed with Lyme-like illness by some medical practitioners.

2.68 The committee notes that there are issues that need further inquiry, such as:

- ways to improve education and awareness about Lyme disease acquired overseas;
- ways to improve Australia's health care system to better meet the needs of Australians with chronic illness; and
- possible pathways for identifying an appropriate name and definition for Lyme-like illness.

#### ***Accessibility and cost of treatment***

2.69 A large number of patients diagnosed with Lyme-like illness expressed concerns about the accessibility and high cost of treatments prescribed by 'Lyme literate' practitioners. 'Lyme literate' practitioners often prescribe a course of treatment

61 Dr Gary Lum, Department of Health, *Committee Hansard*, 20 April 2016, p. 5.

62 See: *Submission 91*; *Submission 396*; *Submission 550*; LDAA, *Submission 528*; Global Lyme & Invisible Illness Organisation / Lyme Australia Recognition & Awareness, *Submission 822*.

63 See: Global Lyme and Invisible Illness Organisation / Lyme Australia Recognition and Awareness, *Submission 822*, p. 27.

64 Mr Matt Chant, *Committee Hansard*, Brisbane, 15 April 2016, p. 14.

65 See: Australian Medical Association, *Submission 456*, p. 4.

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that may include antibiotics and other natural remedies that are not supported by Medicare or the pharmaceutical benefits scheme (PBS).<sup>66</sup>

2.70 The committee heard that the cost of consulting 'Lyme literate' practitioners is very expensive, with practitioners allegedly charging between \$300 and \$900 for consultations.<sup>67</sup> Diagnostic tests used by 'Lyme literate' practitioners also involve significant expense (for example, \$800 for tests in Australia and \$2 000 for tests from overseas laboratories).<sup>68</sup>

2.71 The treatments prescribed by 'Lyme literate' practitioners are also very expensive, often costing hundreds of dollars per week. In one case, a submitter claims to have spent over \$100,000 on treatment since diagnosis.<sup>69</sup> As a result of the high costs, a number of submitters, particularly those receiving welfare or pension payments, note that they have not been able to afford the prescribed treatments.<sup>70</sup> For example, one submitter noted:

One drug for one of the coinfections alone costs over \$1000 per month (and commonly needs to be taken for several months) but \$6.10 if on the PBS. This is just one example and most prescription treatments needed for Lyme and coinfections are unsubsidized on the PBS so it is obvious that it quickly becomes extremely costly to try to gain effective treatment for this illness. The financial burden is enormous and I don't know what I'll do when I run out of money.<sup>71</sup>

2.72 In some cases, submitters highlighted that some treatments prescribed by 'Lyme literate' doctors are not available in Australia. For example, submitters have been referred to a clinic in Germany (Klinik St Georg in Bad Aibling) to undertake 'hyperthermia treatment', where the body is heated to kill off bacteria. This treatment is not available in Australia and costs approximately \$30 000 per course.<sup>72</sup> Other

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66 See, for example: *Submission 136*; *Submission 203*.

67 See, for example: *Submission 101*.

68 See, for example: *Submission 67*; *Submission 119*; *Submission 123*; *Submission 156*.

69 See: Ms Christine Linigen, *Submission 70*. Other submitters have spent between \$20,000 and \$50,000 on treatment. See: *Submission 85*, *Submission 105*; *Submission 121*; *Submission 253*; *Submission 259*.

70 See, for example: *Submission 177*; *Submission 197*; *Submission 201*; *Submission 353*.

71 *Submission 241*, p. 9.

72 See, for example: *Submission 111*; *Submission 125*; *Submission 150*; *Submission 172*; *Submission 187*.

submitters were referred to other similarly expensive treatments in the US or elsewhere overseas (such as ozone therapy in Indonesia).<sup>73</sup>

2.73 As a result of these high costs, a number of submitters have highlighted that they were experiencing significant financial hardship. Many submitters reported having sold or mortgaged their homes, borrowed money from family and friends or moved in with their parents or carers in order to afford treatments.<sup>74</sup>

2.74 Submitters have also highlighted that because Lyme-like illness is not formally recognised, they have experienced difficulties in accessing social welfare payments, income protection insurance and/or early access to superannuation to pay for treatment and expressed concern and frustration that they did not qualify for these payments and services.<sup>75</sup>

2.75 The department noted that to address the costs of treatments prescribed by 'Lyme literate' practitioners, it would welcome an application for a review of treatments to determine whether they could be included in the PBS:

...given the desire by patients and advocates for subsidised pharmaceutical agents, the department would welcome a submission by the advocacy groups to the Pharmaceutical Benefits Advisory Committee for a review of the evidence.<sup>76</sup>

#### *Appropriateness of treatments*

2.76 The committee also heard concerns from medical authorities about some of the treatments offered by 'Lyme literate' practitioners, such as side-effects from antibiotics, infections from intravenous catheters (such as PICC lines) and potential toxins from unregulated medications.<sup>77</sup> These authorities argue that these treatments are not evidence based and risk causing harm to patients.<sup>78</sup>

2.77 For example, one infectious disease specialist submitted:

I have been referred patients with Lyme disease, or such patients have been referred to my colleagues. Sometime they already have another diagnosis

73 See, for example: *Submission 125*; *Submission 129*; *Submission 140*; *Submission 150*. Evidence from submitters indicates that the outcomes of these overseas treatments differ widely. One submitter received hypothermia treatment along with other treatments at the German clinic and experienced a significant improvement in their health, which included increased energy, improved balance and improved cognitive ability. Another submitter who also received treatment at the clinic expressed only a limited improvement in their condition. See: *Submission 24* and *Submission 38*.

74 See, for example: *Submission 447*; *Submission 615*; *Submission 1045*; *Submission 1094*; *Submission 152*.

75 See, for example: *Submission 127*; *Submission 198*; *Submission 304*; *Submission 333*.

76 Department of Health, *Submission 495*, p. 3.

77 Royal Australasian College of Physicians, *Submission 754*, p. 2.

78 See, for example: NSW Health, *Submission 457*, p. 4; Royal Australasian College of Physicians, *Submission 754*, p. 2; Victorian Department of Health and Human Services, *Submission 547*, p. 5; Australasian Society for Infectious Diseases, *Submission 496*, p. [3].

such as Motor Neurone Disease (MND). Then they are offered a different diagnosis in a non-accredited lab, usually overseas. The lab is usually not accredited in the overseas country and charges much more for tests than mainstream labs ...

The patients are often given multiple diagnoses, none of which are seen in Australia such as Babesiosis. In addition the treatment is not standard, even were the diagnosis to be correct and invariably is for much longer than in the IDSA (Infectious Diseases Society of America) guidelines. In other words, even were the diagnosis to be correct the treatment is not standard, and almost always has greater risks of side effects than conventional treatment ...

The circumstances are not universal but there is a cluster of patients diagnosed outside of medicine in unaccredited [sic] laboratories and given unorthodox treatment to the potentially severe detriment of their medical and physical health as well as bearing a great financial and psychological burden.<sup>79</sup>

2.78 In particular, the committee heard concerns about the use of long-term antibiotics to address symptoms ascribed to Lyme-like illness. The Communicable Diseases Network Australia, supported by state and territory health departments, noted that:

There is no evidence to support the use of combination antibiotics, immunoglobulin, hyperbaric oxygen, specific nutritional supplements, or prolonged courses of antibiotics for the management of Lyme disease.<sup>80</sup>

2.79 Associate Professor Samuel Zagarella from the Australasian College of Dermatologists provided the committee with a recent study of a randomised trial of long-term antibiotic therapy for symptoms attributed to Lyme disease in Europe which concluded:

In patients with persistent symptoms attributed to Lyme disease, longer-term antibiotic treatment did not have additional beneficial effects on health-related quality of life beyond those with shorter-term treatment.<sup>81</sup>

2.80 The RCPA further noted that the consequences of long-term antibiotic use can have negative effects for both the individual and the broader community:

Unproven long term broad spectrum antibiotic treatment is not only potentially harmful to the individual patient due to side-effects up to and including death, it is harmful to the patient and the Australian community in general because it promotes the proliferation of multi-drug resistant organisms. This resistance renders all anti-biotics ineffective against

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79 Name withheld, *Submission 462*, p. 1.

80 WA Department of Health, *Submission 529*, p. 5.

81 Professor Samuel Zagarella, Response to question on notice, received 14 April 2016. See: Anneleen Berende et al, 'Randomized Trial of Longer-Term Therapy for Symptoms Attributed to Lyme Disease', *New England Journal of Medicine*, v. 374, n. 13, 31 March 2016, p. 1209.

common (non-Lyme Disease) infections and is a genuine crisis in modern healthcare.<sup>82</sup>

2.81 However, 'Lyme literate' practitioners told the committee that the use of long-term antibiotics was evidence based and in many cases assisted patients to get better. Dr Richard Schloeffel, a Lyme literate practitioner in Sydney, told the committee:

We have treated 4 000 patients in five years. We are currently treating only 1 500 patients. Of the other 2 500 patients we have treated, most are better. They are getting better because they are having an appropriate diagnosis and appropriate treatment, sometimes with long-term antibiotics—oral in the main. But because we have so many sick patients we are doing a lot of intravenous therapies as well, including intravenous antibiotics for long periods of time, which is leading to a positive outcome, but under the same rigor that any intensive therapy would require, and we are doctors who are extremely qualified to do this work.<sup>83</sup>

#### ***Committee view***

2.82 The committee notes that the following issues need further inquiry:

- treatments prescribed for patients with Lyme-like illness, including costs, efficacy and evidence base; and
- the potential for a review of treatments by an expert panel.

#### ***Limitations on 'Lyme literate' practitioners***

2.83 Submitters expressed particular concern that 'Lyme literate' practitioners experience stigma from medical authorities. In some cases, practitioners have ceased providing treatment due to sanctions by or fear of sanctions by medical authorities such as the Australian Health Practitioner Regulation Agency (AHPRA). These submitters argue strongly that 'Lyme literate' practitioners should not be prohibited from treating for Lyme-like illness.<sup>84</sup>

2.84 The committee notes that a number of practitioners who made submissions to the inquiry requested that their name be withheld due to fear of disciplinary action by AHPRA.<sup>85</sup> Mr John Curnow, whose wife suffered from Lyme-like illness, noted in his submission: 'The few doctors that do try to treat [this] Lyme like illness are ostracised and called charlatans by their colleagues'.<sup>86</sup>

2.85 The LDAA also addressed this issue, noting that:

82 RCPA, *Submission 532*, p. 10.

83 Dr Richard Schloeffel, *Committee Hansard*, Brisbane, 15 April 2016, p. 20.

84 See: Mr Greg Watts, *Submission 9*; *Submission 12*; *Submission 77*; Mr Chris Willis, *Submission 127*; *Submission 136*; *Submission 165*.

85 To address these concerns, the committee decided to redact the names of all doctors named in submissions, including Lyme literate practitioners.

86 Mr John Curnow, *Submission 351*, p. 1.

Of serious concern is the increasing level of complaints being directed at doctors who are treating patients with Lyme disease. Over the past three years there have been conditions placed on three doctors (Ladhams, Du Preez and Kemp) treating patients with Lyme disease by the Australian Health Practitioner Regulation Agency (AHPRA). The conditions are specific in response to Lyme disease and relate to the diagnosis, treatment and prescribing practices of the doctors concerned.<sup>87</sup>

2.86 According to the LDAA:

The small handful of doctors who are treating patients in Australia are being bullied and badgered from within their profession and also by AHPRA. It's probable that any Australian doctor that chooses to treat Lyme-like disease will be investigated, given that they administer antibiotics for a longer period of time than the one month treatment protocol and operate outside the ATG's [Australian Therapeutic Guidelines].<sup>88</sup>

2.87 One doctor who made a submission to this inquiry noted that the effect of such investigations was to constrain those doctors in their ability to treat patients:

To my knowledge there are 7 medical practitioners who have been 'targeted' for investigation and / or disciplinary measures. This makes those of us willing to treat this condition fearful of such treatment.<sup>89</sup>

2.88 As a result of limitations placed on their practitioners by AHPRA, some submitters noted that they were no longer able to get treatment. For example, one submitter noted:

In 2013 I came under the care of a Lyme-literate doctor and began receiving antibiotic treatment via a Portacath. I started to notice changes quickly and then improvements within months...

In late 2013 my Lyme literate doctor faced disciplinary action and was [told] he could no longer treat patients with Lyme disease. This left me without a Lyme-literate doctor, or any doctor at all and with no access to assistance with my Portacath for IV treatment. My husband rang many medical centres in our local Redlands area and no one would help me.

As a result my health rapidly declined and I was dealing with a Portacath that clotted and had no medical practitioner to assist with flushing it. Thankfully my husband learned how to manage my Portacath with videos that he found on YouTube.<sup>90</sup>

2.89 In response to this perception, representatives from AHPRA and the Medical Board of Australia (MBA) told the committee at its Brisbane hearing that AHPRA

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87 LDAA, *Submission 528*, p. 25.

88 LDAA, *Submission 528*, p. 28.

89 Dr Adam Nuttall, *Submission 601*, p. 2.

90 Name withheld, *Submission 23*, p. [1]. See also: *Submission 109*.

does not target Lyme-literate practitioners and only responds on the basis of complaints:

... we recognise that there is a perception by some patients that we have targeted medical practitioners who diagnose, treat or have a relationship with Lyme-like illness. I would like to put it quite clearly on the record that this is not true. In all the Lyme-related cases that we are or have been involved with, the board has always acted—not in isolation or on its own behalf—in response to a complaint.<sup>91</sup>

2.90 The Australian Medical Association (AMA) submitted that investigations are initiated on the basis of specific complaints about the individual practitioner:

The very small number of doctors who come before the MBA often have a history of complaints made about them from the public and the profession. The conditions imposed on the registration of any individual medical practitioner are always specific to that practitioner. They do not reflect the Board's view about any disease state or treatment regime. The AMA continues to support the role of AHPRA and the MBA in this respect.<sup>92</sup>

2.91 Representatives from AHPRA and the MBA further stressed that in most cases regarding Lyme literate practitioners, they have decided not to act. In the small minority of cases where AHPRA does act, this is in response to the professional conduct of the practitioners in question:

I would like to point out that in the majority of notifications that have been in some way related with Lyme disease or Lyme in some way, the board has decided not to act—not to act, to protect the public. The matters have simply been investigated and then closed. It is in the small number of cases where there is a greater risk, we perceive, to the public that the board has taken a regulatory action to protect the public. It is on the public record that we have received notifications about practitioners who have diagnosed and treated Lyme disease. I would like to point out that it is not because of the diagnosis that they are there before us, but because of their professional conduct in the management of these patients. It is for these patients that we have taken regulatory action.<sup>93</sup>

2.92 The MBA and AHPRA told the committee that in 2013-14 and 2014-15, of complaints received relating to the treatment of Lyme-like symptoms:

- 9.3 per cent were made by medical practitioners (as mandatory notifications under the Health Practitioner Regulation National Law); and
- 90.7 per cent were made by members of the public.<sup>94</sup>

2.93 The MBA and AHPRA listed some of the concerns related to Lyme disease or Lyme-like illness which have led to an investigation of a medical practitioner:

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91 Associate Professor Stephen Bradshaw, AHPRA, *Committee Hansard*, 15 April 2016, p. 62.

92 AMA, *Submission 456*, p. 5.

93 Associate Professor Stephen Bradshaw, AHPRA, *Committee Hansard*, 15 April 2016, p. 62.

94 MBA and AHPRA, Response to question on notice, received 26 April 2016.

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- the use of unconventional diagnostic techniques (e.g. kinesiology) to diagnose Lyme-like disease;
  - the reliance on non-accredited laboratories to diagnose Lyme-like disease;
  - the potential for financial exploitation of patients, both through the use of overseas non-accredited laboratories and in charging high fees for services;
  - not referring patients with complex diagnoses to specialists, where this would have been appropriate;
  - not managing other co-existing medical conditions once Lyme-like disease was diagnosed;
  - diagnosis of a large proportion of a medical practitioner's patients with Lyme-like disease without considering or excluding other conditions. There is a concern that patients may be deprived of the opportunity to have more appropriate treatment for another condition because the alternative condition is not considered once Lyme-like illness has been diagnosed. Treating Lyme-like illness with long-term antibiotic treatment, in the absence of an identified infection, is of concern. This management is at odds with advice from public health authorities regarding the dangers of antibiotic resistance. We understand that some practitioners are prescribing and administering antibiotics for years (whereas the treatment of Lyme disease is for weeks); and
  - treatment for Lyme-like disease resulting in complications and interacting or interfering with other treatments. Examples include, use of large lines (e.g. PICC lines) to administer long-term antibiotics, which can result in infections and thrombosis, and antibiotics interacting with other necessary treatments.<sup>95</sup>

2.94 The committee heard that AHPRA and the MBA have not considered ways to communicate decisions about 'Lyme literate' practitioners to other practitioners and the patient community. At the suggestion of the committee that this be considered, Associate Professor Stephen Bradshaw from AHPRA told the committee:

To be honest with you, we have not considered what you have just suggested. We may consider that after. I re-emphasise to you that we are not a disease-focused organisation—be it Lyme disease, cancer or whatever. We are looking for good medical practice. It is disappointing that there is this perception out there that we are targeting particular groups; I re-emphasise and will keep re-emphasising that we certainly are not. At the end of the day, the number of practitioners that have regulatory action taken against them on this topic is extremely small. There are huge other areas of practice that have a lot more practitioners before us than practitioners looking after patients with Lyme disease.<sup>96</sup>

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95 Medical Board of Australia and Australian Health Practitioner Regulation Agency, *Submission 533*, p. 3.

96 Associate Professor Stephen Bradshaw, AHPRA, *Committee Hansard*, 15 April 2016, p. 66.

