

## **Assessment of the need for national notification of Lyme disease**

*Joint Criteria Assessment Group (JCAG) for the Communicable Diseases Network Australia (CDNA)*

### *Summary*

A JCAG nominated by CDNA assessed the need for national notification of Lyme disease in Australia against CDNA and PHLN endorsed criteria. The JCAG considered that national notification of Lyme disease is not currently required, and that monitoring laboratory diagnoses of the disease is more appropriate at present. This position may be reassessed if new information about the causative agent(s) of disease in people with Lyme disease-like syndromes in Australia and any known competent vector becomes available.

### *Introduction*

Advocacy groups for Lyme disease in Australia requested that the New South Wales Chief Health Officer consider whether Lyme disease should be made notifiable in Australia and added to the national notifiable diseases list (NNDL). Agreement for the disease to be made nationally notifiable was one of the claims made by protestors during Lyme disease action days on 10 and 11 May 2013. The CDNA was requested to assess the current evidence and report on the need for national notification.

The Australian Government Minister for Health may include a disease in the NNDL if the Minister considers that an outbreak of the disease would be a public health risk. In 2008, the Communicable Disease Network Australia developed a set of criteria which are based on the Centers for Disease Control and Prevention surveillance goals to guide assessment of the need for inclusion of a disease on the NNDL, in order to advise the Minister for Health.(1) Such assessments are carried out by a JCAG, consisting of a CDNA jurisdictional executive group member (chair); a laboratory expert nominated by Public Health Laboratory Network; a local public health unit representative; a project officer, and other experts drawn from CDNA or elsewhere, when required.

The JCAG assess the disease against the endorsed criteria, and then develop a discussion paper for CDNA and PHLN with recommendations about whether surveillance for the condition would be useful and the best method of surveillance as compared to other methods of disease monitoring (e.g., surveys, notifications, using existing datasets).

In this assessment of Lyme disease, the JCAG also considered additional criteria around the risk of spread in Australia and alternative surveillance mechanisms.

### *Composition of the panel*

The JCAG comprised a CDNA jurisdictional executive group member, a laboratory expert nominated by the PHLN), an epidemiologist from the Department of Health and Ageing and an epidemiologist from the National Centre for Epidemiology and Public Health.

### *Assessment against CDNA and PHLN endorsed criteria*

The JCAG met on 1 May 2013 to consider the need for national notification against CDNA and PHLN endorsed criteria. The group found that Lyme disease in the Australian context does not currently fulfil the reasons for national notifications and the majority of surveillance criteria did not apply to Lyme disease, and therefore inclusion on the NNDL is not recommended (Table). No

specific Public Health interventions are available for Lyme disease apart from raising awareness about tick bites and the infection, and therefore public health follow-up of individual cases would not be of value. For example, whilst notification may assist in determining where a case was acquired, there would be no follow-up such as vector control, because wildlife are likely to be included amongst the reservoirs of any causative agent that may be identified in the future, rendering vector control ineffective.

The following additional criteria were also considered by the JCAG:

1. Risk of spread -There is no definitive evidence of a competent vector in Australia, and other modes of transmission such as via the blood supply are very rare (as opposed to diseases such as hepatitis C) therefore the risk of local acquisition and spread is very low.
2. Alternative surveillance mechanisms - National notification is not always the most effective way to monitor a disease, particularly where case definitions are problematic or where notification provides insufficient detail to be of use to inform control efforts. Diseases may be monitored through outbreak surveillance (for example, the OzFoodNet outbreak register), monitoring of laboratory notifications (e.g. the enhanced Listeria surveillance in Australia, novel vectorborne diseases).

#### *International public health significance and notification practices*

In the United States, where Lyme disease is recognised as a common endemic tick-transmitted zoonosis, the disease is nationally notifiable. The most common clinical manifestation is erythema migrans, which eventually resolves, even without antibiotic treatment.(2) The surveillance case definition requires either erythema migrans, or, late stage Lyme manifestations and laboratory confirmation. However, laboratory confirmation may not be required for erythema migrans.(3) Lyme disease is the most commonly reported vectorborne disease and in 2011, it was the 6th most common nationally notifiable disease (<http://www.cdc.gov/lyme/stats/index.html>), with 24,364 cases (7.8 cases per 100,000) reported. Between 2001 and 2010, 70% of cases in the United States experienced symptoms of erythema migrans, 30% arthritis and 8% Bell's palsy, and a range of other symptoms in <5% of patients, with some patients experiencing more than one symptom (<http://www.cdc.gov/lyme/stats/chartstables/casesbysymptom.html>).

In Europe, Lyme disease is considered to be a disease of public health significance, but it is not notifiable Europe-wide. At a 2010 meeting, the European Centers for Disease Control and Prevention failed to reach consensus on whether the disease should be made notifiable.(4) Few individual countries have made it notifiable. Instead of Europe-wide notification, a system of integrated surveillance operates via professional networks who gather and compile the various components; human disease and tick bites, vector and reservoir surveillance.

#### *Recommended monitoring*

The JCAG considered that national notification of Lyme disease is not currently warranted, and other methods for monitoring the disease could be more appropriate. The difficulties associated with developing an acceptable case definition for Lyme disease would reduce the feasibility of data collection. One of the possible ways of improving surveillance is for states and territories to work with public health laboratories to improve data on the number of cases and work with public health laboratories to ensure the appropriateness of laboratory protocols and practices.

This assessment was based on the position that there is currently no definitive evidence of Lyme disease being acquired in Australia. The need for national notification would be re-assessed if any new evidence of locally-acquired disease and the presence of a competent vector become available.

*Other sources of information*

The Chief Medical Officer has convened a time limited advisory committee on Lyme disease (the CACLD): (<http://www.health.gov.au/internet/main/publishing.nsf/Content/ohp-lyme-disease.htm>)

New South Wales Health has issued a fact sheet about the disease:  
[http://www.health.nsw.gov.au/Infectious/factsheets/Pages/Lyme\\_disease.aspx](http://www.health.nsw.gov.au/Infectious/factsheets/Pages/Lyme_disease.aspx)

Table. Assessment of the need for national notification of Lyme disease against CDNA endorsed criteria, 1 May 2013.

Criteria / Surveillance Goal	Applies	Applies somewhat	Does not apply	Rationale for decision/comments
To control the spread of disease (with public health follow up for each case)			✓	Individual public health follow-up of Lyme diseases cases would not be required except for case ascertainment, which is currently problematic. There is currently no known vector, and therefore local transmission from an imported case would not occur. While control of ticks seems a logical control measure should an agent causing locally-acquired disease be identified, it would be very difficult to undertake in practice because the reservoirs of any agent that may be involved are likely to include wildlife.
Outbreak potential			✓	Absence of a known vector, other transmission modes rare and unlikely to lead to outbreaks
Changes in incidence and/or morbidity and mortality		✓		Changes in laboratory practices would likely be the biggest influence on changes in occurrence in Australia, as notified through a surveillance system. Hence, while health authorities want to know about changes to incidence, morbidity and mortality, notification is probably not the best way to assess it.
To estimate the burden of disease			✓	Very difficult to determine the burden of disease because determining a case is so problematic.  Stakeholder acceptance of surveillance case definition based on laboratory confirmation may be problematic and a clinical case definition not acceptable because the disease is too rare.
To monitor trends in the burden over time			✓	This is not a disease known to change rapidly over time
Feasibility of collection			✓	The data are not feasible to collect because lab case definition would not be acceptable to all users. We are interested in the epidemiology and clinical profiles, but there would not be enough notified cases to inform us.
Vaccine preventability			✓	N/A
To assess the effectiveness and immediacy of interventions (e.g. vaccines)			✓	N/A

<b>Criteria / Surveillance Goal</b>	<b>Applies</b>	<b>Applies somewhat</b>	<b>Does not apply</b>	<b>Rationale for decision/comments</b>
To monitor changes in disease characteristics over time			✓	N/A
To enhance understanding of the epidemiology and clinical course of the disease		✓		No evidence of local transmission thus far so it could not inform us
To provide a basis for epidemiological research			✓	Very low frequency of Lyme disease cases make a proper epidemiological research difficult
Community and political concern	✓			High level of concern among groups of advocates for Lyme-like disease in Australia
International concern		✓		No international regulatory concern or programs, interest from the World Health Organization is low. Minimal risk of international spread.
Importance to Indigenous health			✓	N/A
To inform policy makers			✓	There is no particular policy response that would be activated.
To review and assess that proposed surveillance systems are adequately sensitive and specific to achieve these aims			✓	N/A
To review, assessment and refinement of existing control programs			✓	N/A
A developed surveillance strategy			✓	N/A
Post-marketing surveillance			✓	N/A
Laboratory characterisation of organism			✓	Current methods of laboratory diagnosis rely predominantly on the detection of antibody response

## References

1. German RR, Lee LM, Horan JM, Milstein RL, Pertowski CA, Waller MN. Updated guidelines for evaluating public health surveillance systems: recommendations from the Guidelines Working Group. *MMWR Recommendations and reports : Morbidity and mortality weekly report Recommendations and reports / Centers for Disease Control*. 2001;50(RR-13):1-35; quiz CE1-7. Epub 2008/07/19.
2. Stanek G WG, Gray J, Strle F. Lyme borreliosis. *The Lancet*. 2012;379:461-73.
3. Halperin JJ BP, Wormser GP.,. Common misconceptions about Lyme disease. *American Journal of Medicine*. 2013;126:264.e1-e7.
4. Expert consultation on tick-borne diseases with emphasis on Lyme borreliosis and tick-borne encephalitis Stockholm, 23–24 November 2010  
[http://ecdc.europa.eu/en/publications/publications/1102\\_mer\\_tickborne\\_2010.pdf](http://ecdc.europa.eu/en/publications/publications/1102_mer_tickborne_2010.pdf).