Putting Tick-borne Diseases on the Map

Reporting the Reality of Tick-borne Diseases Across Europe
# Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foreword</td>
<td>3</td>
</tr>
<tr>
<td>Executive Summary</td>
<td>4</td>
</tr>
<tr>
<td>Introduction</td>
<td>5</td>
</tr>
<tr>
<td>Expert Steering Committee</td>
<td>5</td>
</tr>
<tr>
<td>Background</td>
<td>6</td>
</tr>
<tr>
<td>Common tick-borne diseases</td>
<td>6</td>
</tr>
<tr>
<td>Notifiable Disease status</td>
<td>6</td>
</tr>
<tr>
<td>Variability in awareness</td>
<td>7</td>
</tr>
<tr>
<td>Calls-to-Action</td>
<td>8</td>
</tr>
<tr>
<td>Policy Makers</td>
<td>8</td>
</tr>
<tr>
<td>Clinicians</td>
<td>9</td>
</tr>
<tr>
<td>At-Risk Groups</td>
<td>9</td>
</tr>
<tr>
<td>Travel and Tour Operators</td>
<td>9</td>
</tr>
<tr>
<td>Employers and Trade Unions</td>
<td>10</td>
</tr>
<tr>
<td>Conclusion</td>
<td>11</td>
</tr>
</tbody>
</table>
Tick-borne diseases are the most common vector-borne diseases in Europe. Between 1999 and 2010, on average 2,900 new cases of tick-borne encephalitis (TBE) were reported every year across Europe. However, prior to the introduction of Notifiable Disease Status in 2012, the numerous disease-reporting mechanisms in Europe may have masked the true impact of the disease. Although a serious disease with potentially fatal consequences, awareness of TBE remains very low within at-risk groups, particularly in countries where the disease is not endemic.

The Health for Growth programme proposal for 2014 to 2020 focuses on supporting areas with potential for economic growth through better health across Europe. One of the objectives is to:

“Encourage innovation in healthcare and increase the sustainability of health systems, to improve the health of the EU citizens and protect them from cross-border health threats”

Tick-borne diseases are very much a cross-border threat, with both residents of endemic areas as well as travellers at-risk. The Health for Growth programme gives policy makers a real opportunity to develop efficient prevention and control programmes for this disease at national and European levels.

In order to tackle this cross-border threat, the true incidence of tick-borne diseases needs to be fully understood through accurate diagnosis and effective monitoring. Based on a clear process for diagnosis, the availability of high-quality laboratory tools effective vaccines, an existing international network of experts and its status as a Notifiable Disease, tick-borne encephalitis was identified as an ideal place to start putting tick-borne diseases on the map. This report outlines a series of calls-to-action, developed by an expert multi-disciplinary steering committee, that give clear and effective guidance to enable key stakeholders to stem the tide of this dangerous and widespread disease. They are further supported by a recent survey of at-risk groups, highlighting a general lack of awareness around tick-borne diseases, as well as confusion around preventative measures.

I hope that all parties take on board the calls-to-action to tackle these diseases in an efficient and proactive way. I have every confidence that this report will raise awareness and support the consistent implementation of European legislation by all Member States. It is vital that no European citizen is unknowingly putting himself or herself at risk of these avoidable diseases.

Karin Kadenbach MEP
Executive Summary

Tick-borne diseases are the most common vector-borne diseases in Europe. Despite this, awareness of these diseases and their potential impact on the public health, policy and travel environments vary significantly at Member State level. To address this variability, the Putting Tick-borne Diseases on the Map Expert Steering Committee was convened to develop a multidisciplinary approach to tick-borne diseases, using tick-borne encephalitis (TBE) as its starting point following the addition to the list of notifiable diseases by the European Centre for Disease Prevention and Control (ECDC) one year ago. Based on their wide-ranging experience, the Steering Committee issued the following targeted calls-to-action:

Policy makers
- National governments to adopt European Centre for Disease Prevention and Control (ECDC) recommendations
- Support required changes to occupational health policies to mitigate the risk of tick-borne diseases
- Explore making Lyme Borreliosis a notifiable disease in the EU

Clinicians
- Implement reporting of TBE diagnosis in-line with ECDC requirements, including post-mortem reporting when necessary
- Develop clinical checklists/pathways for testing for and diagnosing tick-borne diseases

At-risk groups
- Be aware of the risk posed by tick-borne diseases and take appropriate precautions to prevent exposure

Travel and tour operators
- Ensure travellers are aware of the risk of exposure to tick-borne diseases when travelling endemic areas
- Communicate the positive aspects of extended healthcare for travellers

Employers and trade unions
- Ensure employees are aware of the risk posed by ticks when working outdoors
- Develop guidelines and policies to protect at-risk workers (including migrant workers) from the threat of tick-borne diseases
- Raise awareness of travel medicine and its role in occupational health

These calls-to-action have been tested and informed by a survey of groups at-risk of exposure to tick-borne diseases, conducted in October 2013. This report provides an overview of the findings of this survey, as well as further information and guidance on implementing the calls-to-action. Once implemented for TBE, this paradigm – accurate diagnosis and reporting, careful monitoring, education and preventive measures – could provide an effective solution to the cross-border health threat posed by other tick-borne diseases.
Introduction

The Putting Tick-borne Diseases on the Map: reporting the reality of tick-borne diseases across Europe project is a European initiative driven by an expert multi-disciplinary Steering Committee to raise awareness of tick-borne diseases among at-risk groups. This report summarises phase one of the project, providing targeted recommendations for relevant stakeholders to address the threats posed by these serious diseases.

Expert Steering Committee

The Putting Tick-borne Diseases on the Map Expert Steering Committee was convened to help drive the implementation of ECDC’s recommendations for TBE at a national level, and building on the opportunity to address other cross-border health threats in the form of other tick-borne diseases like Lyme Borreliosis. The members of the Steering Committee were chosen to share their wealth of experience, specialist knowledge and wide-ranging influence of working with groups at risk of tick-borne diseases.

The members include:

Ava Easton, Chief Executive, Encephalitis Society
Ava was appointed Chief Executive of the Encephalitis Society in 2011. Prior to this, she spent ten years as the Society’s development manager. Ava is a member of the International Encephalitis Consortium, Vice-Chair of the United Kingdom Acquired Brain Injury Forum, Chair of the Neuro-Infections Charities Network and on the Editorial Board of the Journal of Social Care and Neurodisability.

Professor Dr Martin Haditsch, Medical Head, Labor Hannover MVZ
Prof. Haditsch is a GP and specialist in hygiene and microbiology. He is head of a microbiological laboratory in Hannover, Germany, and co-founder of the Austrian Society of Travel and Touristic Medicine, member of the Editorial Board of the Journal of Travel Medicine and the journal Travel Medicine and Infectious Disease, as well as various other organisations dealing in tropical and travel medicine.

Professor Dr Michael Kunze, Professor and Director, Institute of Social Medicine, University of Vienna
Prof. Kunze has been full Professor and Director at the Institute of Social Medicine, University of Vienna since 1983, and has produced approximately 600 publications. In addition to his university position, Prof. Kunze is Chairman of the International Scientific Working Group on Tick-borne Encephalitis.

Dr Yves Lecocq, Senior Policy Advisor, European Federation of Associations for Hunting and Conservation
Dr Lecocq is the Senior Policy Advisor at the European Federation of Associations for Hunting and Conservation (FACE). Previously, he served as Secretary General of FACE from 1983 to 2012. He is Past-President of the International Union of Game Biologists, a member of the Wild Species Resources Working Group at the International Union for Conservation of Nature, a member of the Wildlife Society and has a degree in veterinary medicine.

Coen van der Veer, Global Wood and Forestry Co-ordinator, Building and Wood Workers’ International
Coen joined the Building and Wood Workers’ International (BWII) as Global Wood and Forestry Co-ordinator in January 2013. He is Second Vice-Chair of the Standing Committee for the wood, furniture and forestry sectors of the European Federation of Building and Wood Workers (EFBWWW), Workers’ Chair of the EU Sectoral Social Dialogues in Wood and in Furniture, and Member of the Working Parties on Occupational Health and Safety of the SSD Wood and Furniture.
Background

A vector-borne disease is a disease spread by the bite of an infected anthropod species, such as ticks and mosquitoes. Ticks are abundant in a variety of habitats across Europe from early spring to late autumn. They feed on the blood of mammals, reptiles and birds and, although the bites themselves are not necessarily dangerous, as a tick feeds it can ingest bacteria, parasites or viruses carried by the animal on which it is feeding. Therefore, each tick bite can become dangerous to humans. If an infected tick bites a human it can transfer the infectious agent into his or her bloodstream, which can lead to serious complications. In endemic areas people who participate in recreational or occupational outdoor activities are at risk of infection. The risk is not limited to those who live in endemic areas, as anyone who travels to an endemic region can be exposed to a potential infection.

**Common tick-borne diseases**

The two most common tick-borne diseases in Europe are tick-borne encephalitis (TBE) and Lyme Borreliosis (also known as Lyme disease). TBE is a viral infectious disease that attacks the central nervous system and can result in long-term neurological symptoms, injury to the brain and even death. TBE is normally found in forests and mountainous areas in at least 17 mostly central and northern European countries. It is a growing public health challenge in Europe with the number of registered human cases of TBE in all endemic regions of Europe increasing by almost 400 percent in the last 30 years. The geographic spread of the endemic regions is also increasing, possibly due to climate change in Europe. Despite this increase, awareness of the disease is very low outside of endemic areas. While there is no specific drug therapy for TBE, it can be prevented by limiting exposure to and early removal of ticks in endemic areas and through vaccination. Lyme Borreliosis, however, is a bacterial infection that can cause a bullseye rash, flu-like symptoms, meningitis and, in advanced cases, polyneuropathy, arthritis and cardiac involvement. While precaution is advised to prevent infection, unlike TBE, there is currently no vaccine against Lyme Borreliosis.

**Notifiable disease status**

In September 2012, the European Commission ECDC recognised the significant health and socioeconomic impact of tick-borne diseases by adding TBE to the official list of mandatory notifiable diseases in the European Union. TBE was already notifiable in 15 European Union and European Economic Area countries, however a reliable estimate of the incidence of TBE was not available due to differences in diagnosis, case definition and reporting.

The goal of the new legislation was to provide high validity and good comparability of TBE epidemiological data so that the disease could be better studied, resulting in more efficient prevention, control and surveillance programmes at national and European levels. At the International Scientific Working Group on Tick-borne Encephalitis annual conference in 2013, over 46 percent of attendees agreed that notifiable disease status is a major step forward for the prevention of new cases of TBE; however, 22 percent still felt that the ECDC’s recommendation would not have an impact on their countries’ vaccination recommendations due to competing health priorities.
Variability in awareness

While awareness of TBE is good in endemic areas, at-risk groups in non-endemic countries are less informed. In a recent survey of at-risk groups, 82 percent of respondents in traveller countries could cite wearing protective clothing to avoid contracting a tick-borne disease and 54 percent could identify using insect repellents containing DEET as a preventative method, but only 22 percent of respondents were aware of vaccination as a method of preventing TBE. This contrasts with 65 percent of at-risk groups in endemic countries with awareness of vaccination for prevention. In the same survey, 71 percent of at-risk respondents overall reported that a tick had bitten them at least once; however, only 39 percent of those bitten have ever consulted a doctor or other healthcare professional for advice. Knowledge of the symptoms of TBE varied widely, from 65 percent of respondents citing brain damage, to only 29 percent citing loss of speech. A total of 54 percent of respondents correctly identified that TBE could result in death.2
The following 11 calls-to-action were developed by the Putting Tick-borne Diseases on the Map Expert Steering Committee and ratified by a survey of 731 respondents from groups at-risk of contracting a tick-borne disease. Respondents included those resident in endemic areas and traveller countries. These calls-to-action outline the actions that relevant stakeholders should undertake to address the threat posed by tick-borne diseases in Europe. Many of these calls-to-action have been designed as “quick wins” that can be implemented quickly and easily, and could have a significant impact on the relevant at-risk groups.

Policy Makers
Although the ECDC’s designation of TBE as a notifiable disease was a significant step in the increased surveillance of TBE, its recommendations are not being implemented consistently across all Member States. Sound recommendations require robust data that must be gathered consistently across Member States. The publication of the Health for Growth Plan 2014 specified that cross-border health threats need common approaches in order to protect EU citizens. National and international bodies need to work together to make tackling TBE a priority.

The three calls-to-action below have been identified as priorities for policy makers:

- National governments to adopt ECDC recommendations
  In order to develop an accurate picture of the extent of tick-borne diseases across Europe, governments of Member States must employ consistent surveillance programmes at the national level. Despite its notifiable status, there is anecdotal evidence that reporting varies from country to country, especially in traveller countries. Administrative burdens should be removed to ensure the reporting mechanism is easily accessible to clinicians.

- Support required changes to occupational health policies to mitigate the risk of tick-borne diseases
  National governments should ensure that occupational health policies include provisions for the prevention of tick-borne diseases for workers whose jobs could put them at-risk.

- Explore making Lyme Borreliosis a notifiable disease in the EU
  Despite the threat posed by Lyme Borreliosis, the lack of a common case definition and the absence of robust surveillance data mean that the true burden of the disease is not known. Policy makers should explore making Lyme Borreliosis a mandatory notifiable disease at the EU level and determine what systems need to be in place to do so.

Have you ever been vaccinated against TBE?

- Yes 21%
- No 79%
Clinicians

Clinicians are a key stakeholder group for implementing the ECDC’s recommendations. In addition, a large part of the responsibility for the goals of the Health for Growth 2014 programme falls to clinicians to identify areas where change is needed and lead the introduction of innovative solutions. In light of this, the Steering Committee has called upon clinicians to:

- Implement an easy and accessible mechanism for reporting TBE diagnosis, including post-mortem reporting when necessary

Clinicians must take responsibility to ensure that all cases of TBE are reported to the relevant national authority in line with its status as a notifiable disease. This should also include post-mortem reporting when a diagnosis has been made but has not been reported prior to a patient’s death. In order to do so, an easy and accessible reporting mechanism should be put into place. Current arrangements can be cumbersome with excessive administrative burden.

- Develop clinical checklists/pathways for testing for and diagnosing tick-borne diseases

While experienced clinicians should recognise tick-borne diseases (at least those with typical symptoms), some doctors may not diagnose them in a timely manner or may not consider them at all. Initially, TBE clinical checklists or pathways should be developed to ensure that cases are not missed or misdiagnosed, which could lead to sub-optimal patient care and under-reporting.

At-Risk Groups

At-risk groups must be aware of the potential threat posed by tick-borne diseases and take action to protect themselves. The Steering Committee has called upon clinicians, policy makers and other stakeholders to support people at-risk of contracting tick-borne diseases to:

- Be aware of the risk posed by tick-borne diseases and take appropriate precautions to prevent exposure

People who are most at-risk are those who engage in recreational or occupational outdoor activities (e.g. hunting, fishing, camping, collecting mushrooms and berries, forestry, farming or military training).

In a recent pan-European survey, two-thirds of respondents at risk of contracting TBE did not know that vaccinating against the disease was an option available to them. Vaccination is considered to be the most effective means of preventing TBE.

Travel and Tour Operators

One group of people who are at risk of contracting tick-borne diseases are those who travel to endemic areas for work, leisure or education. This group of people is particularly vulnerable, as they are less likely to be aware of the dangers of tick-borne diseases and how to take precautions against them. The Steering Committee has called upon travel and tour operators to ensure that travellers are fully informed of the presence of tick-borne diseases when travelling to endemic areas and are prepared with the tools necessary to stay healthy while travelling:

- Ensure travellers are aware of the risk of exposure to tick-borne diseases when travelling to endemic areas

Travellers want to stay safe and healthy when travelling and expect their travel or tour operator to provide them with the necessary information for them to make informed choices about their health while on holiday. This should include information on protecting against tick-borne diseases when they are travelling to endemic areas.

- Communicate the positive aspects of extended healthcare for travellers

Some travel or tour operators may feel uncomfortable providing information on potential health threats like tick-borne diseases to their customers. However, it is their responsibility to ensure their customers’ safety when they are travelling. Travel and tour operators may want to focus on disease prevention as a component of extended healthcare for travellers.
Employers and Trade Unions

People who work in regions of high risk must ensure that they are adopting appropriate protection. People who are exposed to tick-borne diseases every day must have accurate information about the risks of working in endemic regions. Therefore, the Steering Committee calls upon employers and trade unions to protect their employees and members by ensuring that they are fully educated about tick-borne diseases, including the risk factors, symptoms, and preventative measures that are available to them:

- **Ensure employees are aware of the risk posed by ticks when working outdoors**
  All employees who work in at-risk areas should be aware of tick-borne diseases, precautionary measures to avoid exposure and potential symptoms. Employers and trade unions have a responsibility to protect their employees/members from harm and should provide educational resources as appropriate.

- **Develop guidelines and policies to protect at-risk workers (including migrant workers) from the threat of tick-borne diseases**
  Adequate workplace health and safety policies must be in place to protect at-risk workers from the dangers of tick-borne diseases. This should include mandatory protective clothing, tick screening programmes and notification procedures to protect employee health.

- **Raise awareness of travel medicine and its role in occupational health**
  Pre-event risk assessments should always include references to travel medicine when they are taking place in an endemic region. In addition, organisers of conferences, meetings, events or other mass gatherings (including sporting, competitive, religious, cultural or political), should make attendees aware of measures to prevent tick-borne diseases in time to allow for vaccination when appropriate.
Conclusion

The 2014 Health for Growth Programme and the one-year anniversary of the ECDC’s designation of TBE as a notifiable disease provides an ideal opportunity for stakeholders to take action to tackle the threat of tick-borne diseases in Europe. While much progress has been made in monitoring instances of TBE across Europe, inconsistencies still exist at national levels. In addition, there is a discernable gap in awareness between residents of endemic regions and traveller countries in Europe. These issues must be addressed if real progress is to be made across Europe.

If action is taken to successfully control and prevent future cases of TBE across Europe, a similar model could be used in other tick-borne diseases such as Lyme Borreliosis. While there are approximately 85,000 cases of Lyme Borreliosis reported annually across Europe, an accurate picture of the true extent of the issue is not available due to the complexity of the disease and the many possible laboratory practices in use that result in both under and over reporting. For example, recent research from the United States Centers for Disease Control and Prevention estimates that the actual number of people diagnosed with Lyme Borreliosis in the United States is 10 times higher than the number of reported cases. However, despite these obstacles, the proposed TBE paradigm – accurate diagnosis and reporting, careful monitoring, education and preventive measures – could provide an effective solution to this cross-border health threat.
References

1 European Centre for Disease Prevention and Control. Second expert consultation on tick-borne diseases with emphasis on Lyme borreliosis and tick-borne encephalitis. Stockholm: ECDC; 2011.

Disclosure

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