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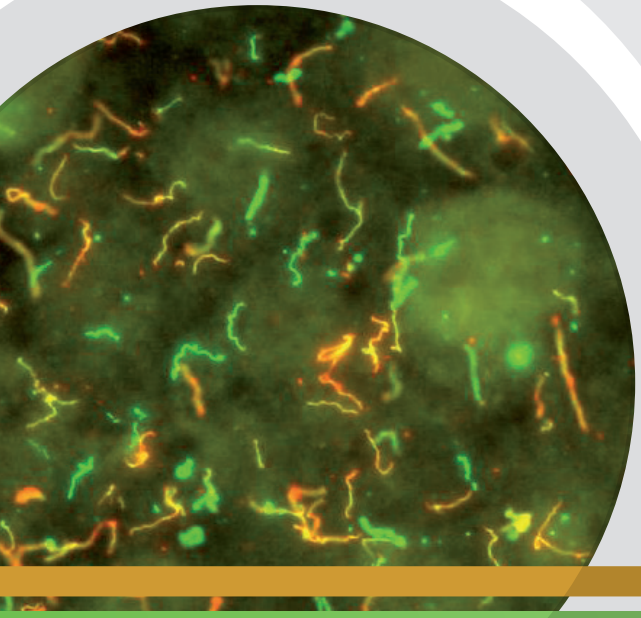

TECHNICAL REPORT

Synergies in community and institutional public health emergency preparedness for tick-borne diseases in the Netherlands

A case study on tick-borne encephalitis and lyme borreliosis

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A case study on tick-borne encephalitis and lyme borreliosis

This report was commissioned by the European Centre for Disease Prevention and Control (ECDC), coordinated by Judit Takács and produced by PREPARE (Public Health Emergency Preparedness Activities for Europe, Umeå University, Sweden.

Authors
Daniel de Vries, Lianne Cremers, John Kinsman

Acknowledgements
We would like to thank the ECDC national focal point for preparedness and response in the Netherlands, and also the ECDC colleagues who contributed to this work. We are very grateful for their help and support.

Netherlands: Fedor Gassner, Corien Swaan, Dorothee Rosskamp, Aura Timen.

ECDC: Massimo Ciotti, Ines Reulet, Judit Takács, Svetla Tsolova, Henriette de Valk (Medical epidemiologist from the French National Public Health Agency, representing the ECDC-coordinated EU Network for Emerging and Vector-borne diseases), Emma Wiltshire and Hervé Zeller.

Suggested citation: European Centre for Disease Prevention and Control. Synergies in community and institutional public health emergency preparedness for tick-borne diseases in the Netherlands. A case study on tick-borne encephalitis and lyme borreliosis. Stockholm: ECDC; 2018.

Stockholm, August 2018

ISBN 978-92-9498-259-9
doi: 10.2900/80366
Catalogue number TQ-09-18-011-EN-N

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Contents

Abbreviations

In this report, names of many Dutch institutes and organisations are translated into English. The following is a list of abbreviations used in the body of the text, including English translations. Appendix 8 shows a complete list of all translated English and Dutch names of the organisations identified in the stakeholder mapping exercise.

Abbreviation	English translation	Dutch name
ECDC	European Centre for Disease Prevention and Control	Europees Centrum voor ziektepreventie en -bestrijding
GGD	Municipal health service	Gemeentelijke Gezondheidsdienst
GLWG	National Green Lyme Working Group	Landelijke Groene Lyme Werkgroep
KNJ	Dutch Hunting Association	Koninklijke Nederlandse Jagersvereniging
LB	Lyme borreliosis	Ziekte van Lyme
NVLP	Dutch Association of Lyme Patients	Nederlandse Vereniging van Lyme Patienten
RIVM	Dutch National Institute for Public Health and the Environment	Rijksinstituut voor Volksgezondheid en Milieu
RIVM-LCI	National Coordination Communicable Disease Control	Landelijke Coordinatiecentrum Infectieziektebestrijding
RIVM-Z&O	Centre Zoonoses and Environmental Microbiology	Centrum Zoönosen en Omgevingsmicrobiologie
SBB	Forestry Service	Staatsbosbeheer
STIGAS	Agrarian Personnel Health Service	Stichting Gezondheidszorg Agrarische Sectoren (STIGAS)
TBE	Tick-borne encephalitis	Tekenencefalitis
TBEV	Tick-borne encephalitis virus	Tekenencefalitisvirus
VBNE	Association of Forest and Nature Reserve Owners	Vereniging van Bos- en Natuurterreineigenaren
VWS	Ministry of Health, Wellbeing, Sport	Ministerie van Volksgezondheid, Welzijn en Sport
ZonMw	Dutch Organisation for Health Research and Innovation in Care	Nederlandse organisatie voor gezondheidsonderzoek en zorginnovatie

Executive summary

Background

Within the context of EU Decision 1082/2013/EU on serious cross-border threats to health, the European Centre for Disease Prevention and Control (ECDC) has initiated a case study project to investigate the synergies between communities affected by serious public health threats and the institutions (both health- and non-health-related) mandated to prepare for and respond to them. The premise of the project is that affected communities are increasingly recognised as key resources that can be used during public health emergencies, and that the concerns, understanding and experiences of the public should be harnessed as an important part of the response.

Aim

The aim of this case study project is to identify enablers and barriers for community and institutional synergies related to preparedness and control of tick-borne diseases. The report focuses on an emerging tick-borne encephalitis (TBE) infection in the Netherlands— where the two first endemic cases occurred in July 2016 — in the context of the widespread and increasing incidence of lyme borreliosis. Specifically, the study aims to:

- identify good practices and patterns of cooperation between affected communities and the official institutions mandated to address tick-borne diseases such as TBE and lyme borreliosis;
- identify inter-sectoral collaboration between health and non-health-related sectors with regard to tick-borne diseases, such as TBE;
- identify model community engagement action for other EU countries.

Methods

A case study research design included the following methodologies:

- Official documents and media reports;
- Interviews with a range of experts working at national and community level (n=26);
- Two focus group discussions with community representatives (n=9);
- Participant observation at the Dutch National Green Lyme Working Groups;
- Stakeholder mapping.

Fieldwork was conducted during a visit to the Netherlands between 17 November and 5 December 2017. The data were subjected to thematic analysis in Atlas.ti qualitative software and UCINET social network software. The analytical framework of the preparedness cycle (pre-incident, incident and post-incident phases) was used to organise the findings. Other topical issues that emerged during analysis were then reviewed.

Findings

TBE during the three preparedness phases

Pre-incident

In the first months of 2017, surveillance collaboration with community-based actors, particularly hunters and herders, facilitated detection of TBE virus in deer and ticks in the Sallantse Heuvelrug National Park. RIVM-LCI subsequently organised a consultation meeting with experts from zoonotic organisations to discuss implications. In order to establish whether transmission to humans was occurring, it was decided to raise awareness among physicians about cases of TBE. Engagement with 'green' (agrarian, estate management, nature conservation, etc.) stakeholders regarding tick-borne diseases continued to focus on LB prevention.

Incident

After physicians were informed, two TBE cases were identified in July 2017. The first known TBE patient had already been part of a LB-oriented citizen science initiative known as 'Tick-radar'. This motivated him to keep and share the tick that had bitten him, which facilitated isolation of the virus. The RIVM-LCI then scaled up to a response team that included zoonotic experts to decide on further measures and investigations, including media communication. In addition, a stakeholder analysis was performed by RIVM-LCI to create an overview of all relevant stakeholders.

During the interviews for this study, there were discussions concerning the pros and cons of inviting other, non-medical stakeholders at the early stage of risk assessment. Although the added value of their participation was recognised, there was also concern that it could dilute the main aim: to objectively assess the medical risk of the threat. However, non-medical stakeholders were included in response implementation and communication. Early

involvement during the implementation phase is valuable, because it ensures understanding of how and why decisions are made, and strengthens understanding of subsequent actions taken.

The decision was made to align TBE response with lyme borreliosis prevention, because TBE preventive measures are very much in line with educational materials developed for lyme borreliosis. This alignment further engaged the Dutch National Green Lyme Working Group (GLWG), a network of green occupational health stakeholders who monitor lyme borreliosis impact and collaboratively host an annual lyme borreliosis prevention week. As case numbers were limited, additional measures such as TBE vaccination were not considered. The issue received hardly any media or public attention in either of the regions, or the affected municipalities.

Post-incident

One new case was identified during the period between August 2016 and the fieldwork activity (in November 2017). There were no comprehensive post-event evaluations because the event was not seen as closed. RIVM has responded to the event in three ways: (1) increasing alertness among medical partners for detection and communication, (2) reviewing public awareness information on tick bites to include more TBE-related information and (3) initiating a number of studies to further examine the extent of TBE emergence.

Vulnerable and hard-to-reach populations

Vulnerable and hard-to-reach populations include hikers, foreign tourists, asylum seekers, pet owners, scout groups, school children, day-care children, garden owners and various volunteers often supporting public institutions. Many of these communities are reachable through the existing lyme borreliosis social networks, particularly by stakeholders who connect with multiple groups ('brokers'). Volunteers who work in green areas often have limited occupational health services and require extra attention.

Community-authority synergies

The Dutch lyme borreliosis social network is large, with many active occupational health-oriented green stakeholders, including patient organisations. Synergies exist between these stakeholders and authorities which facilitate success in public prevention programmes. Close relationships between zoonosis researchers, hunters and foresters involved in this green network led to the detection of TBE virus in deer populations during early 2016. A small section of this network received information about emerging TBE in humans. Furthermore, the detection of the first TBE patient was facilitated through synergy with the citizen science initiative 'Tick-radar'. Despite these synergies, there was little formal guidance on community engagement. Collaboration with patient organisations has required long-term investment in trust building, seen as typical within the Dutch consensus-building culture. The development of synergies with private sector organisations or companies was generally approached with caution.

Communication

RIVM immediately communicated the occurrence of TBE in humans to the medical community, as well as to high-risk groups, key stakeholders in the affected areas, the media, and the Green Lyme Working Group. However, a few stakeholders managing green areas, who had been notified directly of the TBE virus in deer and ticks by RIVM, did not find out about the human TBE incidence through the same channel. Instead, they learned about it through the media. This somewhat compromised their ability to prepare their network for public engagement on the issue. Nevertheless, the timing of the event meant that there was little media and public interest even though the municipal health services were concerned about the unpredictability of media attention. Some respondents pointed out that RIVM has a unique role to play in responding to the public need for evidence-based health information and they felt that the agency should claim this public position.

Inter-sectoral coordination

After health decisions were taken, TBE coordination and response included community-based inter-sectoral stakeholders (e.g. the Forest Service). Some respondents argued in favour of earlier inclusion of inter-sectoral partners, because they could judge the appropriateness of health actions, facilitate timely communication in other networks, increase understanding of the emergency health response and avoid counterproductive measures across sectors. Coordination between the Ministry of Health, Wellbeing and Sport and the Ministry of Economic Affairs is hindered by the differential framing of green/rural space as either 'a risk' or a 'healthy' phenomenon (the 'Green Cloud'). Overall, the 'One Health' approach is seen by many as promising for inter-sectoral coordination because it provides insight into the linkages between processes across governance sectors.

Good practices

As a result of this study, a number of good practices have been identified for promoting collaboration and synergies between the potentially affected communities and institutional preparedness authorities. They include points that have already been implemented to a greater or lesser extent, as well as areas where improvements could still be made. Each of these points, as given below, was suggested by one or more informants of the study.

Promote collaboration and synergies between the authorities and the community

- Use brokers to disseminate preparedness information and engage the whole community network as a resource for early detection, coordination and research.
- Cultivate relationships between zoonosis researchers and community-based monitoring networks, such as hunters and foresters, and promote citizen science in order to increase sensitivity of surveillance.
- Engage other networks of closely-related diseases but clarify differences in risk.
- Integrate community engagement advice in preparedness planning, including disease outbreak guidelines.
- Invest in trust building with community partners who are mistrustful by focusing on win-win solutions and sincerity and being patient.
- Use commercial initiatives as opportunities for public engagement while ensuring that communications are accurate, both to the public and among the parties involved.

Communication

- Continue to support and invest in the maintenance of cross-sectoral, community-based platforms.
- Continue to engage stakeholders who were involved in early detection during all subsequent phases of the response.
- Monitor human resource capacity with respect to local media outreach.
- Support transparency and communication of ongoing processes (e.g. research or decision-making) even if final conclusions or decisions have not or cannot be made.
- Invest in communications capacity in central and regional health authorities to provide an evidence-based voice in public discourse, in close collaboration with community-based partners.

Promote inter-sectoral collaborations and synergies between the authorities

- Conduct a preliminary, comprehensive stakeholder analysis of relevant inter-sectoral partners.
- Provide a careful and timely explanation of the public health decision-making process to all stakeholders involved in the implementation phase.
- Continuously invest in ministerial coordination and consultation by building collaborative capacity, creating win-win scenarios and employing positive experience from previous responses.
- Develop inter-sectoral workflow charts and support ‘One Health’ platform development.

Other important lessons learned that do not directly relate to synergies

- Need for particular effort to reach vulnerable populations.
- Conduct post-incident evaluations.

Background and context

EU Decision 1082/2013/EU (October 2013) on serious cross-border health threats provides a legal basis for collaboration and information exchange between EU Member States, and between European and international institutions on preparedness planning, prevention, and mitigation in the event of a public health emergency. The Decision pays specific attention to arrangements for ensuring interoperability between the health sector and other sectors identified as critical in the event of a public health emergency [1].

As part of the process of increasing inter-sectoral preparedness for serious cross-border public health threats, the European Centre for Disease Prevention and Control (ECDC) has initiated a case study project to investigate the synergies between communities affected by serious public health threats and the institutions (both health- and non-health-related) mandated to prepare for and respond to them. The premise for the project is that affected communities are increasingly recognised as key resources that can be utilised during public health emergencies (this was one of the major lessons learned from the West African Ebola outbreak of 2014–16), and that the concerns and experiences of ordinary people should be harnessed as an important part of the response [31]. Similarly, it is important to understand how and the extent to which institutions in the health and relevant non-health sectors can collaborate in such community-oriented work.

Two EU countries, Spain and the Netherlands, were selected for inclusion in the case study project[1], in agreement with ECDC and the authorities in the countries concerned. Emerging tick-borne diseases in humans have been reported in both countries in recent years, possibly due to environmental changes. These diseases were the focus of the work, which has sought to document the perspectives and experiences of key actors in the health sector; the relevant non-health sectors and the affected communities.

Work in Spain was focused around two cases of infection with Crimean-Congo Haemorrhagic Fever (CCHF) virus that emerged in the Autonomous Community of Castilla y León in August 2016, and is the subject of a separate report. The present report is concerned with the emerging infection of tick-borne encephalitis in the Netherlands — the two first endemic cases occurring in July 2016 — in the larger context of a widespread and increasing incidence of lyme borreliosis.

1.1 Tick-borne encephalitis

Tick-borne encephalitis, or TBE, is a human viral infectious disease involving the central nervous system. In approximately two-thirds of patients infected with the European TBE virus symptoms are non-specific (European Centre for Disease Prevention and Control, 2018), while in 20–30% of patients the second phase of disease involves the central nervous system with symptoms of meningitis, encephalitis or meningoencephalitis. The proportion of patients developing encephalitis increases with age and is highest among the elderly [2]. A third of encephalitis patients experience substantial impairment in quality of life, but mortality is rare (1–2%). There is no specific drug therapy for TBE; however, effective vaccination is available in TBE endemic areas [3]. TBE is caused by the tick-borne encephalitis virus. Three virus sub-types described are European (Western), Siberian and Far-eastern tick-borne encephalitis virus. Ticks, specifically hard ticks of the family Ixodidae, act as both vector and reservoir for TBE virus. The main hosts are small rodents, with humans being accidental hosts. Large animals serve as feeding hosts for the ticks, but do not play a role in maintenance of the virus. European TBE has a patchy spatial distribution of endemic regions across Europe, where climatic and ecological conditions are suitable for circulation of the virus. Global warming may cause dramatic range expansion of *Ixodes* ticks [4], along with changes in leisure habits, landscape management practices and socio-economic influences [5,6].

In 2005, there was no real evidence for a TBE virus reservoir in ticks or wildlife in the Netherlands [7]. Despite incidence in almost all countries across central and eastern Europe since 1980, in 2006 Dutch experts did not anticipate TBE virus movement towards the Netherlands [8]. TBE was only found among people who had travelled outside the country [9]. Using samples collected in 2011, a 2016 study identified TBE virus antibodies in deer as well as TBE-infected ticks in the Dutch Sallandse Heuvelrug National Park, located in the eastern region [10]. Shortly afterwards, in 2016, the first autochthonous case was diagnosed in another national park, the Utrechtse Heuvelrug, in the centre of the country [11]. A person in his 60s with no recent travel history suffered from neurological symptoms confirmed as TBE on 6 July 2016. During clinical observation, the patient gradually improved with no focal neurological deficits present at discharge (day 37), but fatigue and mild subjective cognitive complaints remained. A second autochthonous Dutch TBE case was discovered in the Sallandse Heuvelrug region on 14 July 2016 in a 44-year-old male patient and confirmed on 21 July [12]. By day nine the patient had gradually improved, although tinnitus persisted. Shortly afterwards, a suspected third case was found from the same region. However, this patient had also been in Germany during the incubation period.

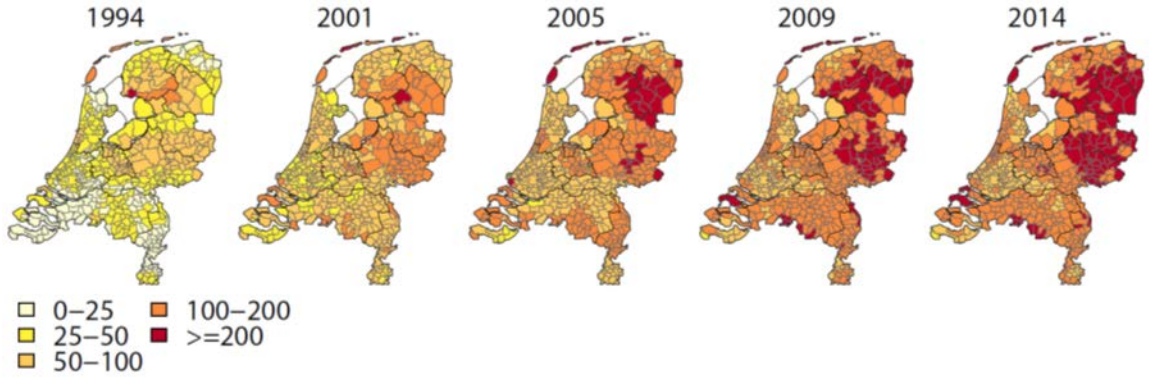
[1] Previous ECDC case studies on institutional preparedness focussed on Ebola [46], MERS [47] and polio [48].

1.2 Lyme borreliosis

Lyme borreliosis is a bacterial disease transmitted to humans through the bite of infected ticks. While infection can be asymptomatic, early skin rash of localised infection, called *erythema migrans*, occurs in about 60–90% of cases, possibly accompanied by flu-like symptoms. If left untreated, the bacteria may disseminate; neuroborreliosis is the main complication, seen in about 10% of infected individuals [13]. All persons exposed to infected tick bites are at risk of becoming infected. No licensed vaccine is currently available, so the main methods for preventing infection are avoidance of tick bites and early removal of attached ticks. Patients with symptomatic infection can be treated with appropriate antibiotics. Early treatment can prevent the risk of developing late stage complications, but even patients with late stage lyme borreliosis can benefit from antibiotics. The pathogenic genospecies are found in *Ixodes ricinus* ticks and vertebrate hosts, including many species of small mammals and ground-feeding birds, which are the principal feeding hosts for larva and nymphs. Adult ticks usually feed on larger animals, such as deer and other larger ungulates. Lyme borreliosis is the most prevalent tick-transmitted infection in temperate areas of Europe, North America and Asia. While overall prevalence of lyme borreliosis may be stabilising, researchers expect its geographical distribution to continue to rise due to economic development, changes in land use and global warming [14].

The Netherlands is among the countries with the highest reported incidence of lyme borreliosis worldwide [15], with an average incidence of approximately 134 cases per 100 000 inhabitants per year[2]. Borrelia-infected ticks are present in many forest and dune areas [16]. In the Netherlands there has been a strong increase in the number of medical consultations regarding tick bites and *erythema migrans*: from 73 000 consultations for tick bites in 2006 to 93 000 in 2009 and an increase in *erythema migrans* patients from 17 000 in 2006 to 22 000 in 2009. A 2011 study has shown that 12% of lyme borreliosis patients suffer from severe infections and 10% show persistent complaints which they attribute to lyme borreliosis [17]. Costs to Dutch healthcare have been estimated at EUR 19.3 million annually [18]. In the Netherlands, 43% of bites occur in forests and 31% in gardens [19]. The number of bites is particularly high among professionals working in the green sector, such as national parks and forestry (36%) or landscaping (15%) [20]. Other risk groups are those spending leisure time in outdoors in parks and forests and schoolchildren [21]. Figure 1 shows the distribution of reported *erythema migrans* in the Netherlands 1994–2014.

Figure 1. Distribution of general practitioner consultations for *erythema migrans* per municipality in the Netherlands 1994–2014. Number of diagnoses per 100 000 inhabitants



Source: Rijksinstituut voor Volksgezondheid en Milieu [22]

If bitten, the tick should quickly be removed to prevent transmission. However, although 90% of the Dutch population has heard of lyme borreliosis, the majority of people are unaware of the consequences. Data from 2007 suggests that only 26% know what to do in the event of a tick bite [23]. In the last decade this figure has most probably increased as a result of efforts to educate the public. Dutch children do seem to know about ticks and lyme borreliosis, and most of them know that checking for ticks is important [24]. Yet only 20% are checked by their parents after having been in green areas. A study of elementary schools in Brabant showed that only half reported taking tick prevention precautions during nature camps [25]. In the green sector, about one-third of all organisations facilitated internal registration of tick bites among their employees, and about half of the employees notify their employers [20].

Finally, because of the difficulty in diagnosing lyme borreliosis, there is ongoing debate in the Netherlands (as in other countries) between lyme patient associations and academic biomedical experts concerning the serological existence of a chronic version of lyme borreliosis. Patients perceive the biomedical conclusion of 'unconfirmed' chronic lyme borreliosis as a denial of their reality, which includes persistent complaints that have a major impact on their day-to-day life. Nevertheless, a lack of laboratory confirmation and the idea that clinicians may perceive the complaints attributed by patients to chronic lyme borreliosis as psychosomatic have led many patients to turn to alternative healthcare, where commercial partners tend to operate on less evidence-based methods. Some have even resorted to healthcare in foreign countries where different regulations allow for long-term antibiotic treatment.

[2] An estimated 23.6% of ticks are infected in the Netherlands, compared to 10.1% European-wide

1.3 Dutch healthcare and outbreak response system

Dutch primary care, with gatekeeping general practitioners at its core, provides a strong foundation of the healthcare system and prevents unnecessary use of more expensive secondary care, while promoting consistency and coordination of individual care. In the Netherlands, the rights of the patient are stipulated in several laws which also cover their relation to providers and insurers, access to information and possibilities for filing an official complaint in the event of maltreatment [26]. Communicable disease control in the Netherlands is managed via a multi-layer hierarchy, flowing from local to national and public to individual (private care), as shown in Figure 2.

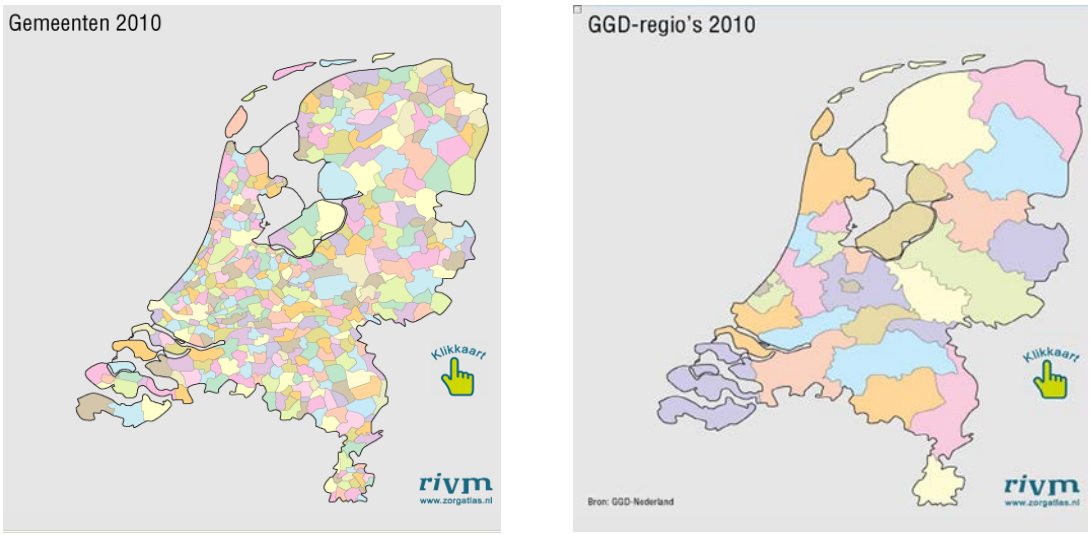
Figure 2. Communicable disease control in the Netherlands

Source: RIVM

In the event of a national public health emergency, the National Institute for Public Health and the Environment (RIVM)'s Centre for Infectious Disease Control (CIb) coordinates the response. Central to the response is one of its five sub-centres[3], the National Coordination Centre for Communicable Diseases Control (RIVM-LCI), which was also the ECDC focal point for this study. RIVM is an independent institute advising on health and environmental issues, with its work primarily commissioned by Dutch ministries and inspectorates. RIVM also undertakes projects within international frameworks. The institute coordinates the control of infectious diseases and is responsible for rapid and efficient communication on outbreaks both at national and regional level throughout the Netherlands. In the event of an outbreak, RIVM is responsible for providing scientific advice on outbreak control measures to the government and arranging for measures to be implemented by health professionals.

According to the Dutch Public Health Act, infectious disease control is the responsibility of the 422 municipalities (gemeenten) (see Figure 3). Serving these municipalities are 25 Municipal Health Service regions (Gemeentelijke Gezondheidsdienst, or GGD), which are aligned with disaster/crisis medical safety regions responsible for disaster medicine and pandemic preparedness: the Medical Emergency Management Regio (Geneeskundige Hulpverleningsorganisatie in de Regio, or GHOR) (see Figure 3).

Figure 3. Dutch municipalities [left] and municipal health service regions (GGD) [right]



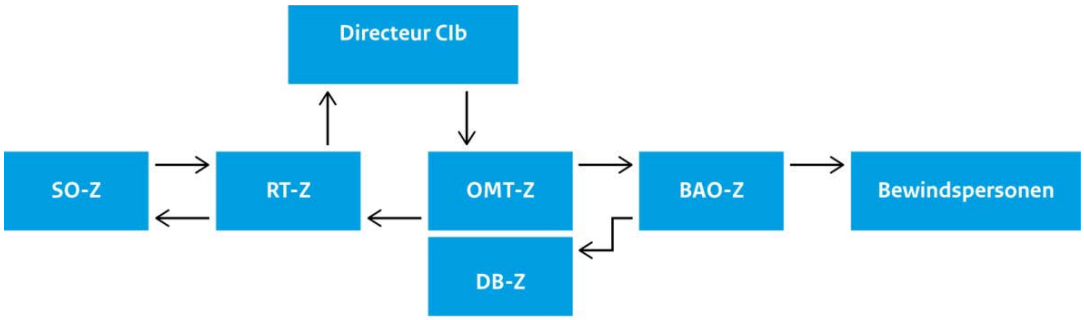
Source: RIVM

[3] The other specialist sub-centres are the Centre for Infectious Diseases Epidemiology and Surveillance, the Centre for Research Infectious Diseases Diagnostics and Screening, the Centre for Zoonoses and Environmental Biology and the Centre for Immunology of Infectious Diseases and Vaccines.

1.4 Zoonotic risk analysis and response structure

During the past decade, the Netherlands has been affected by severe zoonotic outbreaks among poultry (avian influenza in 2003), goats and humans (Q-fever 2007–2010), but also by other slowly emerging wildlife-borne zoonoses such as tularemia (rabbit fever) and lyme borreliosis[4]. In response to these events the Dutch Ministry of Health, Wellbeing and Sport and the Ministry of Economic Affairs developed a collaborative protocol, zoonotic risk-analysis and response structure in 2011 [27,28]. Figure 4 shows the organisational structure[5].

Figure 4. Zoonosis structure, from detection to decision making



CIb: RIVM-Centre Infection Control
Directeur CIb: Director of CIb
SO-Z: Signal Coordination Zoonosis
RT-Z: Response Team Zoonosis OMT-Z: Outbreak management team Zoonosis
DB-Z: Expert Consultation Zoonosis
BAO-Z: Governance Coordination Zoonosis
Bewindspersoon: Policy-maker(s).

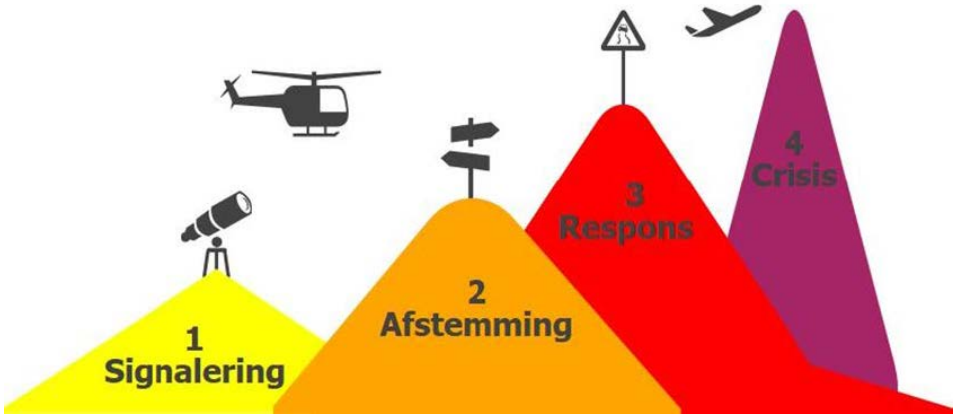
Source: De Jong & Wiessenhaan [28]

Regular medical or veterinary zoonotic signals are discussed at the Signal Coordination Zoonosis (SO-Z), which meets monthly (urgent alerts are sent straight to the Director of the RIVM Centre of Infection Control). The SO-Z evaluates the necessity for setting up a Zoonosis Response Team (RT-Z). In case of urgency, a RT-Z can be called upon any time by its chair (head of centre RIVM-LCI). The RT-Z evaluates the alert and advises the director on measures, including interventions, diagnostics, treatment and communication. If the situation is considered to be a serious threat, the Outbreak Management Team Zoonosis (OMT-Z) advises the ministries on risk, management options and communication. In addition, the Expert Consultation Zoonosis (DB-Z) provides scientific advice ahead of time for non-urgent, complex issues. Finally, the Governance Coordination Zoonosis (BAO-Z) assesses measures provided by the OMT-Z regarding governmental feasibility and desirability. In this process, the OMT-Z invites representatives from patient organisations and animal sectors to provide input.

Within RIVM, the Centre for Infectious Diseases (CIb) uses four scaling-up phases in its emergency response, as shown in Figure 5. Phase 1 is detection and alerting (yellow), phase 2 is coordination (orange), phase 3 is response (red) and phase 4 is crisis (purple).

[4] For zoonotic examples, including more common food-borne infections, see: https://www.rivm.nl/Documenten_en_publicaties/Wetenschappelijk/Rapporten/2017/november/Staat_van_Zo_nosen_2016
[5] For a more detailed version (in Dutch), see: https://www.rivm.nl/Documenten_en_publicaties/Algemeen_Actueel/Uitgaven/Infectieziekten_Bulletin/Jaargang_27_2016/September_2016/Tabellen_en_figuren_september_2016/Figuur_SOZ_artikel.org

Figure 5. Graphical communication of four CIb scale-up phases of emergency response: 1 Alert (Signalering), 2 Coordination (Afstemming), 3 Response (Respons) and 4 Crisis



Source: RIVM

1.5 Definitions

A few key terms are used regularly during the course of this case study project.

'*Community'* – refers to a population directly affected by, or at risk of the disease in question. In this report, we define a community as dynamic since it can change and adapt with variations in environmental, social and political factors. In this study, we distinguish between community and institutional authorities, the latter referring to governmental decision-making bodies, such as the Dutch Ministry of Health, Wellbeing and Sport (VWS), RIVM and the Municipal Health Service (GGD). In this study, there were several communities involved, some of them institutional networks, such as patient organisations, estate owners and managers, veterinary networks, occupational health organisations, and lyme borreliosis patient organisations. In addition to these complex networks, two geographical communities were central foci: the Province of Utrecht hosting the Utrechtse Heuvelrug National Park, which was also the location of the first TBE case, and two community representatives of the Sallandse Heuvelrug National Park, where the second TBE case was detected and where TBE virus was first detected in deer.

'*Synergy*' refers in this report to the added-value that derives from the process and outcome of two or more stakeholders working together towards a common goal. The stakeholders could be either from the community and/or institutional. Any synergy that arises through their collaboration can be seen as something that is greater than the sum of its parts. In other words, the benefits gained through working together are greater than that which stakeholders can achieve alone, and these benefits are, most likely, also mutually shared.

'*Public health emergency preparedness'* is defined as the 'capability of the public health and healthcare systems, communities, and individuals, to prevent, protect against, quickly respond to, and recover from health emergencies, particularly those whose scale, timing, or unpredictability threatens to overwhelm routine capabilities. Preparedness involves a coordinated and continuous process of planning and implementation that relies on measuring performance and taking corrective action' [29].

'*Community engagement*' describes the 'direct or indirect process of involving communities in decision-making and/or in the planning, design, governance and delivery of services, using methods of consultation, collaboration and/or community control' [30].

'*Green partners*' in this report mostly relates to nature-oriented stakeholders, such as owners of estates, landscape management organisations, hunters, forestry managers, etc. It could also include agricultural stakeholders such as farmers and livestock holders.

2. Aims and objectives

This case study project was conducted as part of Lot 2 of an ECDC-funded Public Health Emergency Preparedness Framework Contract (Number ECDC/2014/005). The objective is to identify the elements that should be considered for interoperability and resilience in public health emergency planning, and to support the implementation of EU Decision 1082/2013/EU (October 2013) on serious cross-border health threats.

The aim of this particular case study (Specific Contract No 5 ECD.7247) in both Spain and the Netherlands, was to collect evidence and identify good practices related to community preparedness for public health emergencies in the EU, with a focus on tick-borne diseases. Specifically, the study aims to:

- Identify what has worked well and what may not have worked, with particular attention paid to practices and patterns of cooperation between affected communities and the official institutions mandated to address the threat of tick-borne diseases.
- Where relevant, to identify and analyse inter-sectoral collaboration with respect to community-institutional synergies, and to provide examples of collaborative efforts between health and non-health-related sectors.
- Identify actions that could be taken by other EU countries in the short and longer term.

Case studies were selected through a collaborative process between senior experts at ECDC and country focal points.

3. Methods

3.1 Study design and participants

A case study approach was taken for this project, which was based on several sources of evidence: (a) documents (Annex 2 and 8); (b) 16 national and regional key informant interviews with 21 respondents, and two community-level focus discussion groups with 10 respondents; (c) half a day of participant observation at a National Green Lyme Working Group meeting; and (d) stakeholder mappings, individually obtained during interviews and focus groups. Focus groups included mostly community representatives at risk of tick bites, such as hunters, herders, farmers, camp-site owners, and land/estate owners. Often interviews involved two respondents at the same time. The research team collected all data in the Netherlands between 17 November and 5 December 2017. Annex 1 lists all respondents.

The interview and focus group discussion participant categories, which were discussed and agreed upon in close collaboration with ECDC and the Dutch counterparts (based at RIVM-LCI), were as follows:

National level

- Ministry of Health
- RIVM Centre for Infectious Disease Control (CIb).
- State epidemiologists
- Entomologist or laboratories & diagnostics (RIVM)

Regional level

- Municipal Health Services (GGD Utrecht/Twente)
- Agriculture (livestock) & veterinarians (Wageningen University)
- Regional landscape management
- Forestry Service (Utrechtse Heuvelrug & Sallandse Heuvelrug)

Community level

- Health worker
- Lyme patient organisation representative
- Scout groups
- School representatives
- Private property owners
- Children's farm
- Campground manager
- Municipality employee
- Community green maintenance worker
- Local forestry worker
- Gardener
- Hunter
- Herder.

3.2 Data collection

3.2.1 Research team

The core research team consisted of a Dutch senior medical anthropologist affiliated to Umeå University's PREPARE team who led the interviews, supported by a medical anthropologist, who took notes and asked follow-up questions. A Dutch biologist and Lyme expert deployed by RIVM-LCI attended all interviews and focus group discussions and participated fully by asking questions, and providing advice where appropriate (particularly to local community partners). The RIVM-LCI focal point did not participate in the interviews and discussions, as this was not feasible due to scheduling obligations. Two ECDC public health preparedness experts, a sociologist and a medical scientist (also the team leader) and a medical epidemiologist from the French National Public Health Agency, representing the ECDC-coordinated EU Network for Emerging and Vector-borne diseases, joined the core team for the first two days (27-28 November). The structure of the core team, including anthropologists and a local biologist, proved very effective in reaching out across sectors. In addition, the availability and openness of the Dutch leadership team at RIVM-LCI was a great help in contributing to this report. Finally, the support of the ECDC experts in-country over the first few days was very helpful for guiding the study.

3.2.2 Documents

Prior to the country visit, RIVM directed us to their online resources, and press cuttings collected about TBE and lyme borreliosis were downloaded and analysed. These provided an invaluable overview of the course of events, as well as how people and the media responded. Additional documentary materials were collected from our interviewees during the country visit. In addition, background materials on TBE and LB were identified from online searches and summarized. These included peer-reviewed articles in the published scientific literature as well as formal reports and informal documents. A list of all documents identified for this study can be found in Appendix 2, and media documents in Annex 8.

3.2.3 Interviews and focus group discussions

After discussion and agreement between the study team and the Dutch counterparts (based at RIVM-LCI) on the general categories of respondents, a preliminary list of participants for interviews and focus groups was developed by the RIVM-LCI. A RIVM-LCI employee and Dutch biologist and Lyme expert further coordinated recruitment of all listed participants. After a formal invitation letter explaining the study and informed consent procedures, participants were contacted and if willing to participate scheduled. During the course of the study, a few additional stakeholders were added per request of the study team. Interviews were conducted at RIVM or at the offices of respondents. Community-level interviews and focus groups were held at community-based organisations, such as a care facility for the elderly and the office of a nature conservation organisation. Two interviews (with a patient and a scouting organisation) were held via Skype and two over the phone (Sallandse Heuvelrug forester and Municipal Health Service worker, Twente) for logistical reasons.

An initial set of questions for the interviews and focus group discussions was derived from a literature review previously conducted for ECDC [31]. The questions were structured in a format similar to a theoretical preparedness cycle, based on pre-incident, incident, and post-incident phases [32], and then adapted according to comments received from ECDC and the Dutch counterparts. In this framework, the pre-incident phase involves preparation; the incident phase involves management, monitoring, investigation, and intervention and the post-incident phase involves recovery and identification of lessons learned. The final version of the questionnaire is presented in Annex 3. In order to facilitate the interview and focus group discussion process, the questions were translated into Dutch and sent in advance to the participants. Questions were designed to be broadly relevant to all interviewee categories, but the focus of the questioning varied, depending on the position and particular expertise and experience of each individual interviewee or focus group discussion respondent.

3.2.4 Participant observation

Participants were observed at a half-day meeting of the national Green Lyme Working Group held at a landscape conservation office in Gravenland (Natuurmonumenten) on 30 November, which coincidentally took place during the study visit. During the meeting, stakeholders presented research on TBE and lyme borreliosis, and the group reviewed other ongoing research projects. In addition, a private-sector partner gave a presentation on protective measures and equipment for people working outdoors. The group also discussed coordination of an annual public relations campaign (*Week van de Teek; 'Tick awareness week'*). Observing the meeting enabled us to obtain information about the manner in which partners discussed ideas and issues.

3.2.5 Participatory stakeholder mapping

With the exception of one focus group discussion and two respondent interviews, interview and focus group respondents were consistently asked to start the conversation by drawing a stakeholder map from their point of view. Each respondent was asked if they could map on a blank piece of paper the different stakeholder/interest groups or groups that have previously been involved in preparation for tick-borne diseases, or a hypothetical case with a higher incidence. We also asked which stakeholders were considered community-based or governmental. Respondents who had experience with the actual TBE event were also asked which stakeholder they thought was missing during the response. While this exercise was mainly a means of engaging with stakeholders and facilitating communication, it did provide an overview of how each stakeholder saw themselves in relation to other partners in the community. Analysis was conducted by the study team (see Section 3.3).

3.2.6 Ethical considerations

Written informed consent was obtained from all interviewees and focus group participants, who were assured that nothing they said would be ascribed to them within any reports and/or subsequent publications. They were also asked to agree to the listing of their name and title as respondent in the report. The consent form is included in Annex 4.

3.2.7 Data analysis

During qualitative analysis, notes from the interviews and focus group discussions were subjected to thematic analysis, using Atlas.ti qualitative data software. A set of pre-defined codes was used as a starting point, based on the questions from the interviews, with additional codes included as they emerged. A list of the codes and their thematic classification is shown in Annex 5. Since the organisation of the questions in terms of the emergency preparedness cycle was challenging due to the limited emergency response situation of only two TBE cases, data analysis strategy shifted towards the underlying infrastructure of lyme borreliosis as an enabling context for a real or hypothetical upscale of TBE. In the end, the analysis focused on the synergies, barriers and enablers of community engagement, with some emphasis on the theoretical preparedness cycle mentioned above.

Stakeholder maps were collected and their data compiled into UCINET software, with symmetry forced into the matrix. The resulting social network was complemented by an attribute file listing detailing whether each actor was a government authority or a community-based organisation, as well as their medical, educational, environmental, or animal health identities.

4. Findings

4.1 The lyme borreliosis / TBE community

During community engagement, what does the 'community' actually look like? Respondents were asked to visually map stakeholders they would turn to in the event of a major TBE event (see Methods). Most perceived that the general lyme borreliosis network was the same as that used for any work on TBE, and consequently did not make a distinction. Figure 6 shows the combined result of the stakeholder mapping exercise. The size of the nodes indicates the extent to which an actor is a broker[6] or the amount of influence an actor has on others based on their unique connectedness. Removal of brokers from the network will be the most disruptive for communication between other nodes.

The results show an extensive network that indicates a key role during TBE events and/or lyme borreliosis prevention work for a set of brokers (represented by a larger-sized node) mainly in the health field. These are the Municipal Health Services, RIVM's Centre for Coordination and Outbreak Control (RIVM-LCI), family doctors and the Dutch Association of Lyme Patients, one of two Dutch patient organisations. The major exception to this health-oriented set of brokers is the national Green Lyme Working Group (GLWG). The GLWG is a network coordinated by the Agrarian Personnel Health Service (also known as STIGAS) and the Association of Forest and Nature Owners (VBNE), and includes collaboration with an extensive network of 'green' partners (e.g. estate owners, landscape management, wildlife experts, etc.). Moreover, GLWG brings together occupational health and medical providers interested in reducing tick-borne disease in their workforce and a lyme patient organisation.

Next to the GLWG brokerage, we can see how other smaller brokers connect many community-based outliers. Furthermore, a number of other perhaps unexpected key brokers appear, such as the Royal Dutch Hunting Association or the VBNE. We conclude that while only a few actors were active during the 2016 TBE event, there is a community-based preparedness and response potential in this network that can be exploited in future TBE outbreak situations. The next section describes how respondents reported having made use of this network during the 2016 emergence of TBE disease. This social network is, of course, limited by the particular selection of respondents for the study as well as recall bias during the exercise. Nevertheless, it provides a relatively unique overview of social relationships which otherwise remain hidden in more static stakeholder analyses, such as the analysis developed by RIVM-LCI (Annex 6).

[6] Measured using UCINET's 'betweenness centrality' statistics.

Figure 6. Entire lyme borreliosis / TBE social network based on stakeholder mapping

The size of the nodes indicates brokerage ('betweenness centrality'), or the amount of influence a node has on others based on its unique connectedness.

Red denotes stakeholders using a health perspective.
Blue denotes stakeholders using a non-health perspective.
Diamond shapes denote government authority, circles are community-based.
See Annex 9 for Dutch names.

4.2 Tick-borne encephalitis in the three preparedness cycle phases

4.2.1 Pre-incident phase

Community engagement in detection

Although in 2005 researchers had found no evidence of a TBE virus reservoir in ticks or wildlife in the Netherlands [7], reports of TBE virus-neutralising antibodies in wildlife and cattle in Belgium prompted researchers to reinvestigate in 2010. During analysis of serum from 317 deer by the Dutch Wildlife Health Centre in 2015, six (2%) were found positive, five of which were from Sallandse Heuvelrug National Park (see Figure 7). In addition, TBE virus RNA was detected in two ticks from the same location [10].

Figure 7. Spatial distribution of roe deer positive for TBE virus

The researchers concluded that TBE virus had been endemic to the Netherlands for at least five years prior to 2005, and deemed the isolated location of these results to be 'striking and unexplained'[7]. They argued that TBE virus may be prevalent at other locations in the Netherlands. In order to aid detection, zoonotic researchers involved with the study explained how they had been working together with both estate management and green actors, such as Natuurmonumenten, a national nature conservation organisation, and the Dutch forestry service (Staatsbosbeheer). They had also worked with animal groups such as herders, hunters and the Dutch Wildlife Health Centre to organise sampling. Collaboration between health specialists and green partners had developed as a result of previous cooperation between Wageningen University & Research and RIVM as part of a research programme called 'Shooting the messenger' (2012–2017[8]). Explicitly aimed at integrating disease prevention into environmental/nature management, the initiative supported community-based stakeholders with laboratory analysis in return for information and data sampling. An informant from RIVM involved in the cooperation said: 'We asked all stakeholders how they could help us and how we could help them. We approached people who work in these areas, and then awareness grew that also people using these areas for recreation purposes were exposed to ticks. They became interested in the prevention of tick bites.' RIVM facilitated this situation by spending 20% of its tick-borne disease research budget on stakeholders. As a result of this collaboration, the researchers held three sessions a year with the green and animal stakeholders to discuss the problem of ticks in their areas, and they developed a local risk management tool focusing on hotspots.

[7] They theorised that the occurrence of TBE virus in such isolated locations may be the result of dense beech tree coverage (beechnuts are a major food source for roe deer and rodents).
[8] https://www.wur.nl/nl/nieuws/Geintegreerde-aanpak-natuurbeheer-en-ziekte-van-Lyme.htm

Coordination meetings with zoonoses and health experts

The emergence of TBE virus in deer and infected ticks was discussed as a potential threat at the routine, monthly Signal Coordination Zoonosis (SO-Z) meeting. Upon detection, RIVM's National Coordination Centre for Communicable Disease Control called a dedicated coordination meeting to specifically discuss and assess the risk of human transmission. At this stage a standardised list of stakeholders was consulted to assess the full risk. In the case of TBE virus detection, these stakeholders included experts in entomology, microbiology, epidemiology, public health, the local Municipal Health Service (GGD Twente), clinicians, veterinarians, occupational health doctors and wildlife experts. The RIVM communication group also attended the meeting, as is common during all response phases.

At the coordination meeting, it was concluded that human TBE cases were not likely to be expected on a large scale. It was decided to raise awareness of TBE among clinicians in the affected region (Sallandse Heuvelrug) and to provide information to microbiologists and public health specialists (through a direct mailing service (LabInf@ct) and an alert report #2860). RIVM then informed green partners and hunters who had participated in the serological survey, the visitors' centre at the Sallandse Heuvelrug National Park, and the regional Forestry Division. According to respondents, they were asked to restrict distribution of the TBE information so as not spread unnecessary anxiety. The source of this request remained unclear. On 30 June 2016, RIVM reported that Dutch *Ixodes ricinus* ticks had tested positive for TBE virus-Eu in the Sallandse Heuvelrug region [34][9]. The institute also broadened its investigation to sheep, goats, raw milk and cheese.

Q-fever inter-sectoral experience motivating a medical priority

A previous, major outbreak of Q-fever (*Coxiella burnetii*) among goats between 2007 and 2010 was considered the largest registered incidence in the world [35]. This event served as the main reference model on how to deal with a zoonotic disease event. In particular, the Q-fever event was the first time that it became evident that inter-sectoral collaboration was required as a result of a zoonotic outbreak, leading to a plethora of coordination challenges [36]. One particular point of discussion had been whether inviting private sector organisations and non-professionals (including patients) to participate would be an effective use of resources in the Q-fever emergency response. A major sticking point was the balancing of commercial and agricultural risks versus human health risks. For RIVM-LCI, one lesson learned was that content-related engagement was not desirable, because inter-sectoral involvement would influence ('cloud') medical decision making, which is the top priority. Accordingly, non-medical involvement should begin at the response phase, based on the risk assessment presented by the medical core, and with full involvement of a broader group of stakeholders in terms of the measures to be implemented. The medical advice provided by the risk assessment coordination meeting would be presented to other collectives at ministerial level (e.g. through the Outbreak Management Team Zoonosis, OMT-Z), after which inter-sectoral discussions could take place.

Conclusion

During the pre-incident phase, collaboration with community-based actors, particularly foresters, hunters and herders, facilitated detection of TBE in deer and ticks. After detection, RIVM-LCI invited a selection of zoonotic experts to discuss implications, while retaining medically-based decision-making.

4.2.2. Incident phase

The first human TBE case and citizen science synergy

On 6 July 2016, one week after the alert report and Lab-Infact communication, the Municipal Health Service in Utrecht region were notified of a 67-year old man with serological confirmation of TBE. Interviews confirmed this and further analysis of the tick suggested that the tick bite had occurred in a national park in the Utrecht region (Utrechtse Heuvelrug). In response to the detection, the Utrecht Municipal Health Service interviewed the TBE patient and collected and further analysed ticks in collaboration with RIVM. On 21 July, a second patient was confirmed [12], a 45-year-old gardener living on the border of the Sallandse Heuvelrug National Park. Patient interviews excluded the possibility of the virus having been contracted during foreign travel. Shortly afterwards, a third case was identified in the Salland region, although this person had been in endemic areas of Germany during the TBE incubation period.

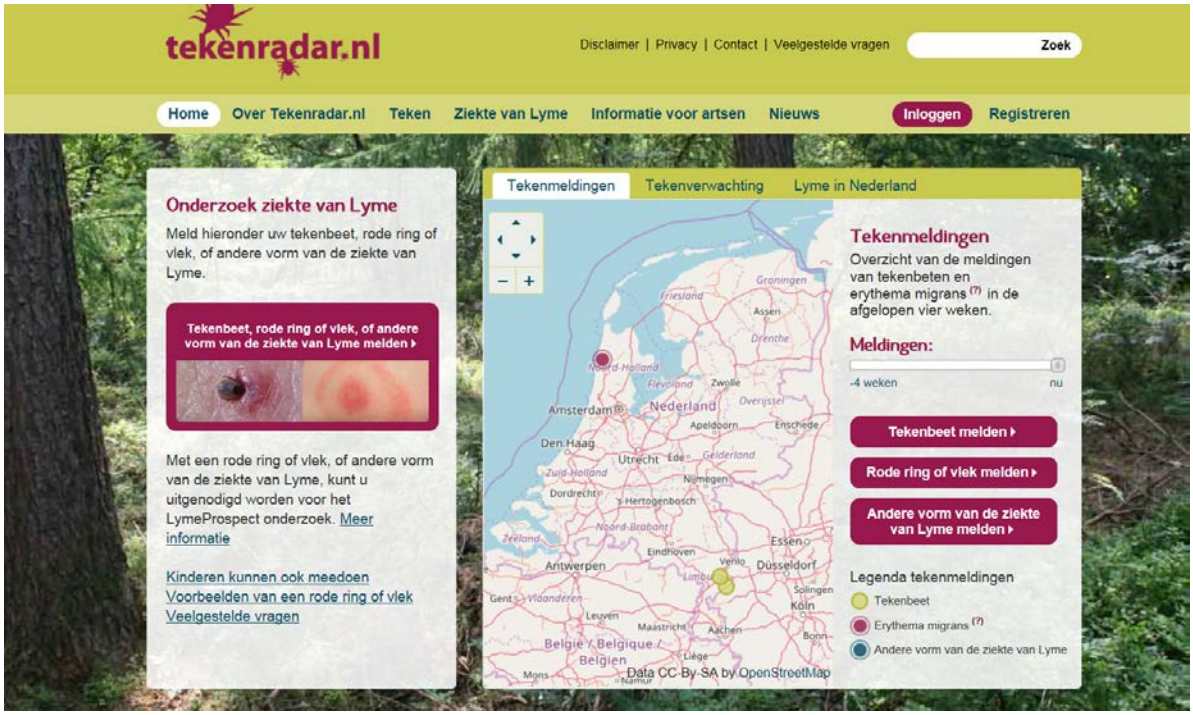
Table 1. Timeline of 2016 TBE event

Date	Event
30 June	RIVM notifies of TBE virus reports in animals
6 July	First case confirmed
14 July	Second case admitted to hospital
21 July	Second case confirmed
21 July	National press release concerning the first case
Shortly afterwards	Third case notified but had travelled to Germany

[9] Public announcement on the website: https://www.rivm.nl/Documenten_en_publicaties/Algemeen_Actueel/Nieuwsberichten/2016/Teken_encefalitisvirus_in_Nederland_aangetroffen

The clinical detection of TBE just one week after the initial alert was seen as a success story. However, from a community engagement perspective, there was an additional influence that facilitated isolation of the virus . Before becoming infected and showing symptoms, the first human patient had already been part of a citizen science initiative called 'Tick-radar' (https://www.tekenradar.nl/). The Tick-radar was developed by the University of Wageningen, RIVM epidemiologists and biologists with experience in participatory science projects (e.g. the Natuurkalender[10]). The tool, which is available via an internet site, predicts and monitors incidence visually on a map for each municipality (Figure 7). The tool is also available through a mobile phone app 'Tekenbeet' released by RIVM as a public information tool for lyme borreliosis prevention. Since 2012, the site has provided education and outreach concerning lyme borreliosis and tick-borne diseases, while also enabling people bitten by ticks to register their location, including contact information and, if relevant for pending research, send in their ticks. As the first human case diagnosed with TBE in the Netherlands had been a Tick-radar participant, he understood the importance of keeping the tick after being bitten[11]. This facilitated the finding of the source. As a rapid communication on the first case in the Eurosurveillance journal confirms: 'Fortunately, the patient had saved the dead tick, which was positive for TBEV by qRT-PCR with a Ct value of 21' [11].

Figure 7. Screenshot of the home page of the Tick-radar, 14 January 2018



Source: https://www.tekenradar.nl/

Adapting to new stakeholders in a zoonotic context

After confirmation of human cases, RIVM-LCI decided to scale-up to develop a response team. Respondents from the institute mentioned that the zoonotic context meant they had to adapt in terms of stakeholders, some of whom - particularly those from the green sector - were new to RIVM-LCI. RIVM-LCI convened a meeting to conduct a stakeholder analysis for risk groups, detailing relevant relationships for people working in green areas, and those visiting outdoor areas. The aim of the meeting was to optimise collaboration with relevant organisations to reach risk groups as best as possible. A report on the meeting stated:

'An important point during an infectious disease incident is that during the event each stakeholder manages their own environment and works with their own networks. In a stakeholder analysis there is a certain aim you want to reach by building on the idea that one organisation cannot reach all by itself. You want to organise a network of organisations that start to collaborate to reach the common goal.' [37]

[10] The idea of the 'Tick-radar' (and other similar radars such as the mosquito radar) is based on the 'Nature Calendar' (*Natuurkalender*) which enables citizens to give their observations on annual natural cycles, such as the migration of birds, thus monitoring, analysing and predicting the cycles over time. This WUR-RIVM-volunteer project also measured ticks density throughout the country with the help of nature education volunteers for a period of 10 years. This provided more detailed information on tick activity period, tick infection rates, tick density and tick risk areas.

[11] RIVM had encouraged people to send in ticks for research purposes before this occurrence, but this programme had been closed by the time the incidents occurred. However, the patient had still had the foresight to save the tick. At present, people are not being encouraged to send ticks in to RIVM anymore for lyme borreliosis diagnosis, because no firm conclusions on lyme borreliosis can be made on the basis of the tick, and research studies have sufficient participants (see: https://www.tekenradar.nl/over-tekenradar-nl/overig-tekenradar-onderzoek/wat-moet-ik-met-mijn-teek-doen).

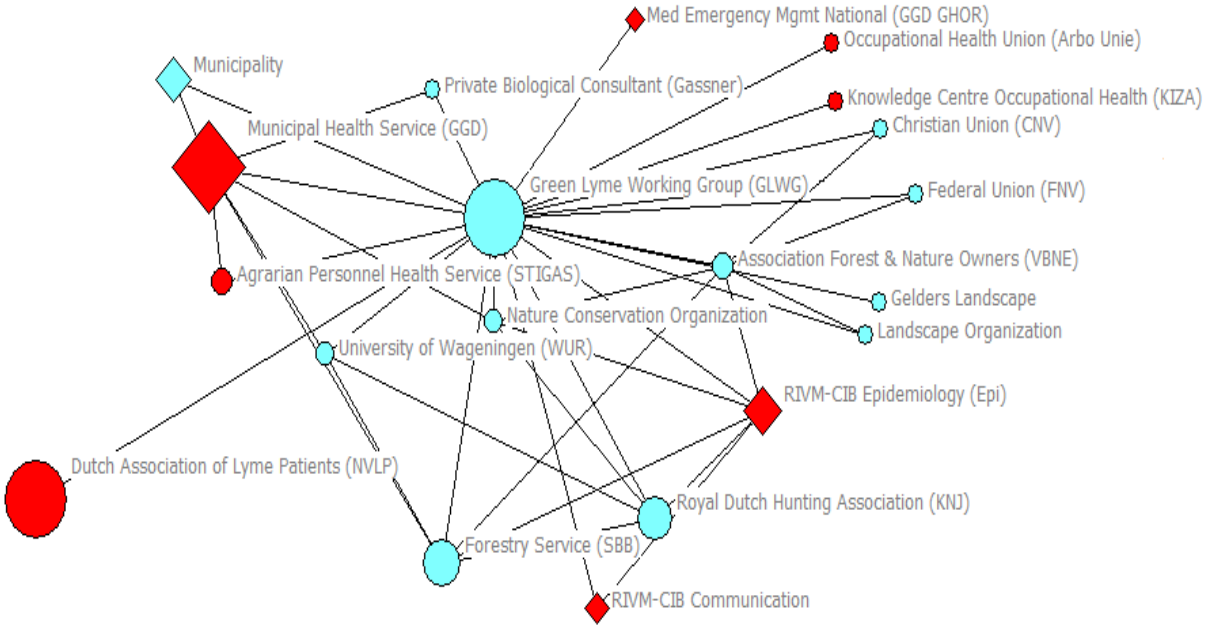
During the stakeholder analysis the coordination group identified the information needed by stakeholders from the coordination group, and what the stakeholders could offer RIVM-LCI. With respect to risk groups, although it was easy to ascertain what information was spread by different organisations, a more difficult task would be to know if the information actually reached the audience and if there was compliance. The coordination team wanted help from all stakeholders in collecting this information, while at the same time being able to support the same stakeholders by providing ready-made information. For medical care stakeholders, close collaboration with professional associations was seen as an effective way of reaching risk groups, while simultaneously raising awareness of TBE among medical doctors. Dissemination of information and updates regarding ongoing studies concerned with TBE were seen as supportive instruments for this stakeholder group. With respect to government and media institutions, emphasis was placed on accurate, audience-specific, up-to-date information to avoid both unnecessary public unrest and the spread of incorrect information. Finally, the report noted that the large number of stakeholders belonging to knowledge institutions and other associations were key partners for supporting ongoing research studies and dissemination of information to patients. If studies showed that certain population(s) were more at risk of TBE, more local parties could be included in direct information outreach. RIVM-LCI singled out the Association of Forest & Nature Owners (VBNE) as an especially relevant partner, as they are an umbrella organisation including various green partners. Figure 8 shows the result of the full stakeholder analysis.

Public alignment of TBE in the community-based lyme borreliosis prevention network

Since no new cases emerged in the immediate period after detection of the first two patients, the response team agreed that the infection would probably be slow to spread and efforts shifted towards prevention and media or public communication. As the generic processes for dealing with TBE overlapped with those for lyme borreliosis, RIVM-LCI took the decision to align response efforts within lyme borreliosis prevention. This meant that although the Municipal Health Service involved in the initial coordination meeting started notifying general practitioners, neurologists, children's doctors, microbiologists and municipal politicians about TBE, public health communication (e.g. to scout groups, campers, those spending time in recreational areas, nature organisations, libraries, etc.) focussed more broadly on lyme borreliosis prevention. One of the main reasons for this was that lyme borreliosis included a 'behavioural' or 'actionable perspective' since the swift removal of ticks can reduce infection risk considerably. TBE virus, on the other hand, is transmitted shortly after the bite, so quickly removing the tick will be much less effective in preventing infection. Public education regarding TBE should therefore emphasise tick bite prevention rather than the early removal of ticks. However, at present, public information still focuses on early removal, since research has shown that people do not take preventive measures in the Netherlands.

The focus on lyme borreliosis made it easy to connect with the network of actors involved in a national public health prevention campaign. 'Week of the Tick' is an annual event coordinated by the National Green Lyme Working Group (GLWG). GLWG developed in the 1990s as a result of outdoor workers' concerns regarding the impact of tick-borne diseases, particularly lyme borreliosis. The Group has now has become a think tank and communication platform, exchanging information and participating in research on lyme borreliosis and TBE. At the GLWG meeting observed for this study, updates on current RIVM studies were shared, with the explicit aim of sharing results before the next Week of the Tick event. The Dutch focal point (RIVM) and its municipal partner (GGD) joined the meeting, which occurs twice a year. Figure 8 shows the social network of this multisector group.

Figure 8. National Green Lyme Working Group sub-network



Red denotes a dominant health focus.
Size of node denotes brokerage roles in the larger network analysis (shown in Figure 6)

What is striking about this visualisation is how the GLWG group integrates both health and environmental stakeholders in its tick prevention efforts. The network is an excellent platform that facilitates public health prevention and response among green partners in the event of an epidemic[12].

It was challenging to try and exploit existing relationships that developed through another, closely-related disease domain. As one respondent noted: 'TBE was a very different situation, but the same people were involved. They were not used to these emergency questions, needed more information to answer these questions and started to become anxious. It appeared that there were other relations with the same stakeholders in case of threat. We needed experts to explain and soothe the situation.' In particular, first-line health workers appeared to need more information and began to wonder why they had not been vaccinated. There was a lack of clarity as to why the decision had been taken to align the diseases. At the time of the study the emphasis was still on lyme borreliosis rather than TBE, although RIVM has been slowly integrating TBE into its outreach.

Little social media or media attention

Several major Dutch newspapers and websites were analysed, and a full list of references and summaries appears in Annex 8. Before the first case, only a few media reports had been published about TBE virus having been found in deer in the Sallandse Heuvelrug National Park. On 21 July 2016, before detection of the second and third cases, RIVM sent out a national press release reporting on the first TBE case, and explicitly mentioning the Utrechtse Heuvelrug as place of infection. After 21 July, all media publications were factual and short and referred to the RIVM website. However, none of them addressed the second and third cases. Topics included the background of the disease, modes of transmission and symptoms. News articles placed emphasis on ticks spreading the virus to humans and the low risk of contracting TBE. A few articles compared the risk of contracting TBE with the risk of contracting lyme borreliosis (nu.nl, Telegraaf, NOS, NRC, AD). Symptoms were described and various articles advised seeing a medical practitioner if having complaints (dokterdokter.nl, NRC, GGD). All reports mentioned preventive measures, such as checking the body for ticks and removing them, avoiding tall grass, and wearing long trousers in green areas. One report mentioned precautions for landowners (NRC 31-3-2017). Medical practitioners were asked to take TBE into consideration (Blik op Nieuws, WUR). Some reports briefly referred to RIVM research on deer. Three articles mentioned the German name for TBE, *fruhsommer-meningoenzephalitis (FSME)*. Only NRC and VBNE mentioned specific risk groups, such as hikers and workers in the outdoor/green sector. Overall, it can be concluded that media attention was accurate but that there was little of it.

The municipal health services involved did not directly contact the media, because communication was coordinated nationally through RIVM's communications department. After the RIVM-LCI national press release, local media made contact, and journalists visited the affected areas and concluded: 'nobody was worried.' In both regions there was little media or public attention, not even in the affected municipalities. In Utrecht, authorities received only ten

[12] When meetings start, the Chair states: 'I always start the meeting with a message. Everyone communicates in their own way to their supporters. But we do this together at the same moment. And that is what we do in the *Week of the Teek* [Tick awareness week]'.

questions. One possible reason for the low response, particularly in the eastern part of the country, might have been that the sickness is typically known under the German name of Frühsommer-meningoenzephalitis and thus the link to TBE was intuitively not made. Only one citizen asked to be vaccinated in that region. A respondent from this area mentioned that 'even in the village where the second patient lives nobody spoke about it, and these people had a lot of social contacts. Not even the local politicians wanted information.' Respondents thought that during the period when the TBE cases emerged the media appeared to be preoccupied with other events, such as the ongoing riots in Egypt, Zika virus, and many people were away on summer vacation.

At first, respondents from the Municipal Health Services downplayed the media issues, noting that lyme borreliosis is an issue which only receives a few questions each year from the public (about 15). They also noted that people tend to first visit the RIVM website before going to local health authorities. In particular, they said: 'We try to keep low key. We did not know whether to exaggerate the problem, get people worried. So we always refer to the same source: the RIVM website.' They indicated that they had some agreement with RIVM that local translation of news was their responsibility and that they had some media capacity in-house. Nevertheless, the unexpected lack of response by the media was perceived as a blessing in disguise for one of the two municipal health authority respondents, since there had been concern that the media might exaggerate the news. If this had happened, it would have led to serious capacity issues because at the time they were also dealing with an outbreak of scabies and mosquito-borne diseases. We also learned that the second TBE case in the Sallandse Region, for whom foreign travel could not be excluded as cause - had not been communicated to the media at all.

RIVM benefits from a social media rumour control system, using available software packages and dedicated communication staff. If needed, communication staff can find ways to contact active, well-connected social media users to engage with them in private dialogue. By showing some understanding, the institute helped to alleviate frustration among users. Some of the social media users even worked with RIVM, providing information on developments. Here too, we can conclude that no significant misperceptions or rumours were reported during the event and none have been reported since.

Medical priority in inter-sectoral engagement

The Dutch risk assessment system focusses on a medical perspective. The decision was taken by RIVM-LCI to continue to do this as it was perceived as crucial to retain medical objectivity when assessing the medical risk of a potential threat. For this reason RIVM-LCI respondents considered it important to limit the stakeholders involved in the risk assessment to those with medical functions. The role of the community was recognised by public health respondents, but not considered important until the stages following the medical risk assessment (i.e. when a response action would need to be discussed and decided-upon based on the medical risk assessment.) Discussions were held with the respondents concerning the pros and cons of inviting other, non-medical stakeholders at the risk assessment stage. Although the added value of such participation was recognised, there was also concern that this inclusion could dilute the main aim of objectively assessing the medical risk of a given threat. The respondents explained that even the participation of policymakers should be avoided at this stage, to ensure a strict medical assessment. At the national level, the involvement of other sectors was considered as relevant in the subsequent response phase, when actions need to be taken that could have an impact on communities and other stakeholders.

Respondents within RIVM were not united regarding this issue. A practical reason for more participation was that broader community engagement during coordination might become helpful. For example, when discussion went beyond health risk assessment and moved to the action required 'to avoid counterproductive measures being taken'. An additional reason was that community organisations are not always familiar with the public health emergency preparedness and response procedures. For example, hunters do not automatically consider the municipal health service as a point of entry for information. At a children's farm, the coordinator told us that many of their volunteer-run sister organisations did not know where to get their information from.' In this case, involvement in response at an earlier stage could be of value, because it would ensure understanding of how and why decisions were made, strengthening relations and improving understanding of subsequent actions taken. Respondents from outside RIVM suggested some alternatives to direct inclusion of more stakeholders during coordination or response. For example, a separate action meeting directly after public health decisions had been taken, or contacting stakeholders right after coordination meetings to provide updates. Another consideration would be to involve communities at the pre-event phase when systems were being developed and assessed. By including their contribution at this stage, ownership could be shared, offering a greater understanding of the processes involved in the risk assessment phase.

Indirect communication to key stakeholders

An unintended consequence of the decision not to include inter-sectoral partners in coordination until later was that the green partners in whose areas the TBE cases had appeared received information of human TBE cases indirectly through the media. This issue was especially difficult for those who had been notified by RIVM representatives to withhold initial information on the detection of TBE virus in deer, to avoid anxiety among their audience and workers. In response, information was carefully managed. From the Municipal Health Service in one of the affected areas we understood that employees in the green sector had already heard about TBE virus in

animals, but one of the green sector managers expressed frustration that the information about the first human case was disseminated only through the media:

> 'Suddenly I read it in the paper, which meant that the carefulness of spreading the information does not hold anymore. I would have though it appropriate if RIVM had notified us of the press release in advance, because I could then freely spread the information with my terrain managers before they also read it in the paper. Because after all, they are the ones who get questions from the public.'

An additional challenge noted by one of the RIVM researchers was that this development endangered relations between zoonotic researchers and community-based nature partners. One respondent expressed it like this: 'Because they were not updated about TBE being a life threatening virus. Everyone thinks nature is public domain, but it is owned by someone. We should have involved them from scratch.'

Community engagement through health guidelines

For TBE, RIVM-LCI had developed a health guideline in October 2010, which was amended on 21 July 2016 because of the new human-TBE epidemiological situation. Additional resources were then added on 15 August 2017. However, the most recent version only mentions the first human case (neither the second, nor the suspected third) in its epidemiological section. A link to the digital map of infectious diseases in the Netherlands shows the incidence of tick bites, not further information on TBE. As with other infectious disease guidelines, this guideline does not detail advice on community engagement or stakeholder analysis from a preparedness or response perspective, despite the fact that zoonosis involves a strong inter-sectoral component. It does mention a very limited list of four risk groups: 'foresters, woodcutters, campers and hikers.'

One of the respondents, who is active in the National Green Lyme Working Group, said that when TBE virus was found in deer in some of the areas of the Netherlands, there were concerns among green and nature organisations regarding the risk to employees. Since RIVM research is ongoing as to the specific risk of TBE, guidance has remained open. As a result, the working group has started looking at models from neighbouring Germany to provide advice to its members. One issue was the request for vaccination from people working in the field experiencing many tick bites. At present, RIVM does not advise vaccination.

Conclusion

While detection of the first human TBE case was clinically driven, it was thanks to the citizen science initiative 'Tick-radar' that the first TBE patient knew to keep the tick that had bitten him. With only a few cases and little media interest, the RIVM response team decided to align TBE response with lyme borreliosis prevention efforts. This was also due to the fact that post-bite behavioural action has a limited effect on the chances of contracting TBE infection. This action facilitated a second community engagement synergy through the involvement of the National Green Lyme Working Group, which collaboratively hosts a lyme borreliosis prevention week, also applicable for TBE control. Motivated by a green occupational health perspective, the National Green Lyme Working Group has a vested interest in integrating any tick-borne diseases into their mission. However, we also learned that the new emergency structures which were introduced through TBE resulted in a different orientation and role for these partners. While the RIVM-LCI team was aware that new stakeholders had to be included in the zoonotic context, efforts were still made to keep decision-making free of other (inter-sectoral) influences. Information about the first human TBE case reached green actors through the media instead of through their own channels, leaving outdoor workers unprepared for dialogue with the concerned public. Finally, no information on community engagement was included in the TBE disease guidelines.

4.2.3 Post-incident phase

At the time of this study, no comprehensive, post-event evaluation had been performed. Lessons learned had not been explicitly gathered or fed back into planning, because the TBE event was not perceived as significant enough. While the emergence of TBE is still under investigation, only one new case of TBE was identified in the period between August 2016 and our fieldwork in November 2018. In addition to the previously mentioned case reports, a small review was written by the Utrecht Municipal Health Service with inter-sectoral partners. It notes that since the first medical communication about human detection of TBE, the number of TBE diagnostic tests has increased four-fold (to around 100 requests per year) [38]. A presentation by RIVM researchers during the National Green Lyme Working Group meeting suggested that in response to the event RIVM has moved its focus to increasing awareness among medical partners to improve detection, and adjusting public education about tick bites to include more TBE-related information. In addition, RIVM has initiated a number of studies, including some with community-based partners[13].

[13] Ongoing studies at the time of writing include: (1) Another serological study with the Dutch Wildlife Health Centre among deer, (2) Serological research among small grazing animals in collaboration with the Animal Health Laboratory Service in Twente and Utrecht, (3) TBE virus serology among 100 neurological patients from 2015 and 2016 in the region of Twente (eastern Netherlands) to trace suspected neuroborreliose and negative lyme borreliosis serology, and (4) TBE serology among people with high occupational risk of tick bites (mostly outdoor occupations).

4.3 Vulnerable and hard-to-reach populations

Interviews identified several hard-to-reach or vulnerable populations and groups in relation to tick-bites. Those mentioned several times were pet owners, scout group members, schoolchildren, day-care children, garden owners and volunteers working in green areas. The Municipal Health Services in Utrecht noted the need to focus on asylum seekers who live in forested areas. In addition, hikers and foreign tourists were identified. These groups appear to be disconnected from the general prevention campaigns and to lack systematic registration and monitoring systems, even though they often frequent green areas or even own large pieces of land. For example, the national scouting board has only run a few small preventive campaigns, limited to standard information on the website, a poster for management, and some collaboration with the Week of the Tick campaign. Local scout groups are often not aware of risks, and do not regularly monitor young scouts. Moreover, parents do not always check for ticks at home or ticks are discovered too late. There is a lack of organised engagement with these groups on the part of medical practitioners, the National Green Lyme Working Group and RIVM and few instances where there is a possibility to interact, such as during the patient conference *So Strong* [39], focusing on alternative healing approaches.

Another example of a vulnerable group are volunteers working with the many lyme borreliosis and TBE institutional stakeholders. Many hunters are in contact through voluntary organisations, however these lack occupational health services. The Utrecht Region Forestry Service has 230 volunteers many of whom go into the field. Although they are trained in lyme borreliosis prevention and provided with tick repellent clothing, they have no access to the occupational health services of the Forestry Service. The situation is even worse as regards children's farms, which are often volunteer-run, where neighbourhood volunteers come and go. In some instances, more professionally managed children's farms with membership of the Association of Children's Farms (vSKBN) that include occupational health services often function as information brokers for their volunteer-run partners.

In some cases, occupational health services supporting vulnerable populations appear insufficiently familiar with the extraordinary impact of LB in the green sector. One respondent noted that his agency had shifted contracts because of dissatisfaction with the attention to tick-borne issues. One suggestion that came up in a community focus group is to facilitate better involvement of organisation that accredit occupational health services (e.g. Groenkeur, Erbo) to ensure that appropriate LB questions, information and preventive structures are implemented annually.

4.4 Additional lyme borreliosis-related community engagement findings

Information in this section does not directly concern the TBE event, but relates to observations derived from the more general lyme borreliosis context which are relevant for disease preparedness and response coordination in general.

4.4.1 Lyme borreliosis patient synergies

A remarkable situation in the Netherlands is the way in which the lyme borreliosis patient population and the authorities have managed to find collaborative space, despite inherent tensions resulting from the difficult diagnostics of Lyme disease. Lyme borreliosis patients often share their perception that health authorities are not doing enough because they define the 'Lyme patient' much too narrowly. Both patient organisations are vocal on this matter, but the Tick bite Patient Organisation (*Stichting Tekenbeetziekten*) in particular strongly supports this point of view. In 2010, frustrations led the Dutch Lyme Patient Organisation (at that time still including patient activists who later started the separate Tick bite Patient Organisation) organising the collection of 70 000 signatures through an online forum called Lymenet[14] to express their dissatisfaction to the Ministry of Health, Wellbeing and Sports[15]. Despite scepticism from the Dutch Health Science Council , the Ministry responded by initiating a number of projects. These included (1) funding mechanisms for further lyme borreliosis research through a new Programme for Lyme coordinated by the Dutch Organisation for Health Research and Innovation in Care (ZonMw) and (2) the establishment of the new Dutch Lyme Expertise Centre (still under development at the time of this study). However, there were tensions as to who should lead this new Centre, and the patient organisations and RIVM negotiated for three years on this point. Eventually, this lengthy process led to the developing of sufficient mutual trust for collaboration, after both sides realised that they shared the same overall goal and were both acting with integrity. (The Dutch form of consensus building is a well-known cultural practice referred to as the '*polder model*') [40].

While the impact of the Dutch Lyme Expertise Centre remains to be seen, the participation of the NVLP patient organisation in this collective is perceived as a success, with high expectations regarding media and public outreach[16]. On the other hand, the pace of this development has been met with disappointment by a number of the respondents. Furthermore, some respondents argued that generally the balance might have gone too far in favour of the patient agenda, particularly since patient representatives are included in the selection committee of the ZonMw scientific

[14] LymeNet Nederland: Informatie over de ziekte van Lyme. 19-01-2018. URL: https://www.lymenet.nl/.
[15] The initiative enlisted the support of prominent politicians (some also suffering from lyme borreliosis) and consumer advocates, and included a persistent letter campaign by patients to the Ministry of Health (VWS)
[16] The Foundation for Tick Bites left the collaboration shortly after agreement was reached.

programme on lyme borreliosis. They fear that this may lead to the exclusion of projects that are relevant to other priorities than the chronic (treatment-focused) patient perspective, such as research into vaccination or other preventive measures. Another concern relates to the risk of organisational changes within the patient organisation itself, which as a volunteer organisation is susceptible to the shifting political agendas of individuals. Since the organisation has a vocal minority which is critical of slow (or uncommunicated) research results, there is a real risk that the current collaborative mood will disappear.

4.4.2 Private sector synergies

Synergies with private partners exist, but most respondents said that they treated such collaboration with caution (even some of the lyme borreliosis patients, who saw few alternative options). These include private laboratories or clinics with treatments that are not evidence-based or only to a limited extent (e.g. ILADS, Waldorf); pharmaceutical laboratories providing alternative diagnostic tests that are not always validated (e.g. Innatoss Laboratories), or companies providing insect repellent sprays (e.g. Care+). Privatisation is also visible in the green sector, for example in the form of commercial camping companies, or municipalities outsourcing basic landscape and nature management services. One focus group respondent noted that managers of commercial vacation parks often do not talk about the issue as they are driven to protect their commercial image of being 'clean and green.'

Local governments interested in business development capitalise on disease-specific private initiatives. The Province of Flevoland aimed to attract lyme borreliosis-related businesses, and even some major stakeholders such as the Amsterdam Medical Centre and Wageningen University Bioveterinary Research sent in proposals. Yet scepticism about the initiative dominates because the entrepreneurial spirit of self-sufficiency and small amount of incubation capital appeared difficult to combine with the public health agenda. As a medical expert noted: 'Their only goal is to generate money. They are not trying to solve the disease but use the disease as economic input for the province. Up to now nothing came out of it, so I do not think this is a valuable partner.' In all cases, private synergies do show potential for public health risk communication and awareness-raising and are a form of community engagement. However, as they still come with commercial agendas, these conflicting interests are an issue of concern for tick-borne disease prevention and preparedness. Respondents proposed the involvement of external quality control watchdogs as a means of positively exploiting this type of synergy.

4.4.3 Inter-sectoral coordination

More coordination

At all levels respondents emphasised the need for more inter-sectoral coordination. Despite the previous Q-fever experience, the placement of agrarian and environmental issues under the Ministry of Economic Affairs remains a challenge for the integration of health preparedness issues further down the chain. Lobbying for inter-sectoral coordination between the Ministries of Health , Agriculture, Nature and Husbandry and Economic Affairs is slow-paced. This is particularly problematic for the financing of environmental or agricultural interventions that reduce health risks[17]. One barrier to infectious disease preparedness is what was referred to by respondents as the 'Green Cloud', seen as the tendency by non-health stakeholders to protect the public image of green and rural (agricultural) space as 'healthy' (and a source of tourist and leisure revenues). Added to this are structural issues, such as the misalignment of governance between the Ministries. Respondents explained: 'The problem is while we work for Municipal Health Services, our regional partner for whom we are responsible, the Ministry of Agriculture works with provinces. They say provinces should make policy. And so they cross each other.'

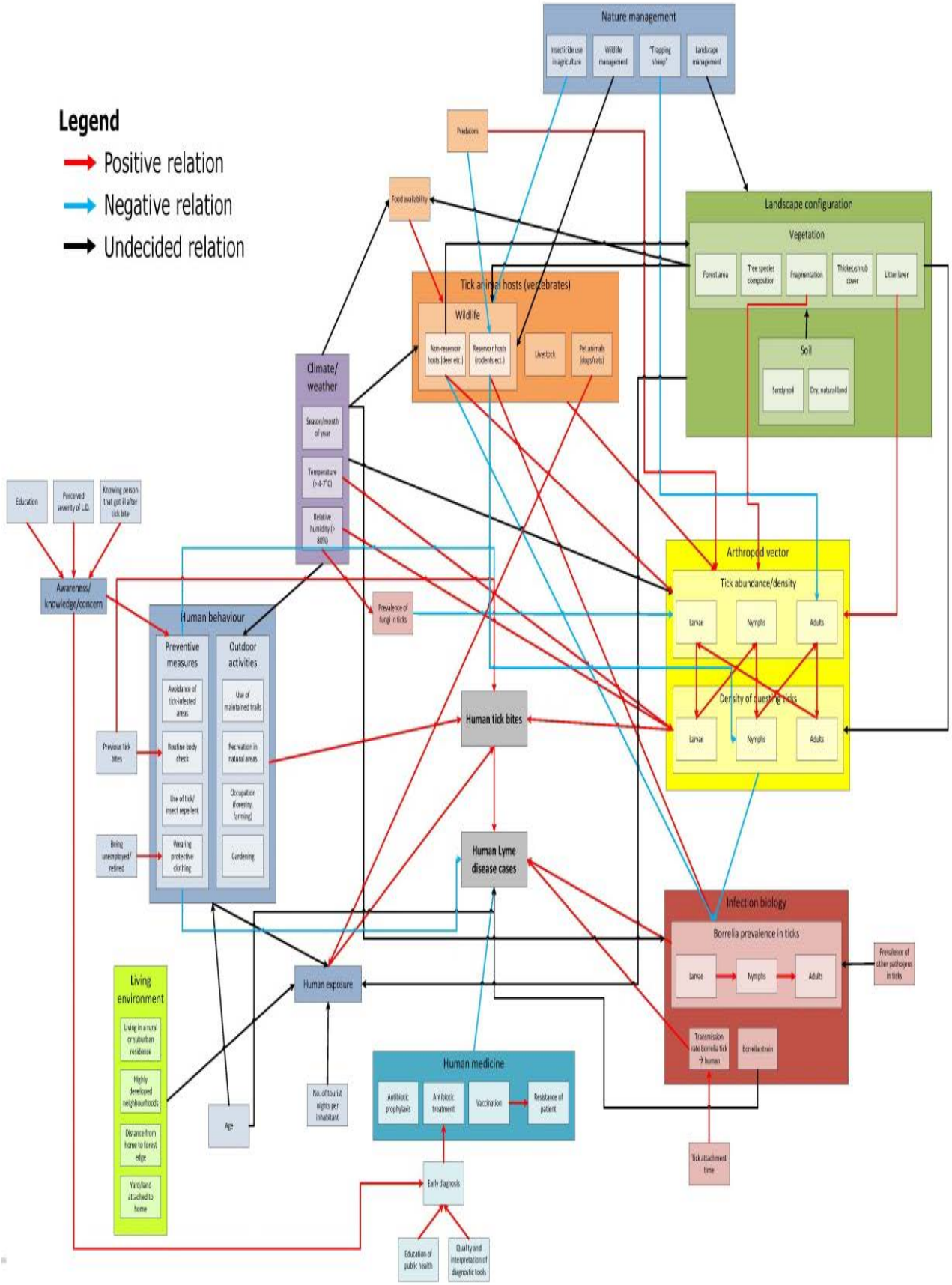
The inter-sectoral collaboration of the National Green Lyme Working Group (GLWG) has already been noted. The GLWG mostly represents green, patient and occupational health stakeholders, but has less involvement with some of the wildlife, veterinary and animal groups. One respondent from an animal group also expressed some criticism that GLWG 'had a hard time getting to active measures, because everyone was pointing fingers to others suggesting some action was their responsibility.' At the local level, the two Municipal Health Services (GGDs) who both had experience of TBE only recently launched initiatives for closer collaboration with green partners. Most Municipal Health Services appear not to be making such strategic efforts, although local initiatives exist with other zoonotic diseases.

Promising 'One Health' approach

The 'One Health' approach was often mentioned as a promising strategy. However, there was also criticism of this concept, since it appears to be very health-centric and does not place equal priority on agrarian, ecological or economic issues. 'Health in all policies' was suggested as an alternative (referring to the Dutch *Integraal gezondheidsbeleid*, or 'comprehensive health policy'). The value of 'One Health' was illustrated by a schematic diagram created by researchers at Wageningen Bioveterinary Research that shows the drivers of lyme borreliosis across inter-sectoral dimensions [41,42] (see Figure 9). One of the main uses of this diagram has been to encourage stakeholders to see how their work processes are connected to those of 'others', facilitating respect for each other's background, and encourages communication and trust building to overcome inter-sectoral hurdles.

[17] One respondent provided the example of the desire for a fence for two camping ground sites to prevent deer from coming in. The cost, EUR 20 000 over 20 years was more than camp-site owners could afford.

Figure 9. Schematic diagram showing the drivers of lyme borreliosis across inter-sectoral dimensions



Source : De Vos et al., 2016 [42]

4.4.4 The role of RIVM in public dialogue

Many respondents emphasised the important role of RIVM which is responsible for public communication and awareness. While RIVM-LCI hosted rumour control communication specialists relevant for TBE, respondents generally perceived the Dutch health authority to be cautious in engaging the public in discussions on lyme borreliosis[18]. A medical respondent remarked: 'Sometimes those creating social anxiety receive way too much attention from the media. I think it is the role of RIVM to keep it all real. A role that is not about reassuring that everything will be all right, but about informing the public of the facts... They have to be visible as an authority showing evidence and explain their conclusions.'

Respondents argued that RIVM researchers could be more communicative in explaining to the public how, or how well they are doing their job and reaching their conclusions. People trust researchers more when they explain to them how their evaluation and research process works. Respondents from outside RIVM also noted that an entire network of community-based partners is available to support such a role.

RIVM has recently been making efforts to ensure that communication is a more central strategy. Capacity issues seem still a barrier to this management shift. Within the RIVM-LCI, a number of initiatives such as a tick-specific mobile phone app [43,44] and efforts to develop and evaluate a game for school children [45] do indicate that public education and engagement is a priority issue. The RIVM communication department is aiming to work closely with the new Dutch Lyme Expertise Centre and has favoured the Tick-radar citizen science initiative as one of its priorities for communication of news. However, some community-level focus group participants felt that the communicative value of the easily accessible database and website still has much more potential.

[18] One research-oriented respondent indicated a wish and willingness to reach out to patient organisations at a lyme borreliosis conference that showcased unconfirmed ('alternative') treatments often attended by more 'activist' lyme borreliosis groups. However, leadership at the institute considered this too risky and the outreach did not happen. Unfortunately, because medical doctors also do not go to these conferences to explain their position, there is no dialogue.

5. Good practices

This final section outlines a set of 17 good practices for promoting collaboration and synergies that have been identified in this study. They include actions that have already been implemented in the Netherlands to a greater or lesser extent as well as areas where improvements could still be made. These actions are presented as suggested objectives that may be worked towards, both by the authorities in the Netherlands and those in other EU Member States.

Promoting collaboration and synergies between the authorities and the community

- Use brokers to disseminate preparedness information and engage the whole community network as a resource for early detection, coordination, and research. The network of community actors engaged with lyme borreliosis/TBE is large and wide, extending deep into the community. A 'Whole Community' approach may be considered here[19], whereby community-based actors are not only seen as a means for disseminating preparedness information, but also as a resource for early detection, coordination, response and research. Specific attention should be given to community actors with links to multiple social groups, such as green occupational health professional organisations.
- Cultivate relationships between zoonosis researchers and community-based monitoring networks such as hunters and forestry workers, and promote citizen science to increase sensitivity of surveillance. For zoonosis in particular, community-based groups have a direct stake in detection. Close relationships between zoonosis researchers and hunter or foresters, for example, can be exploited to facilitate early detection, as can citizen science projects such as the Dutch Tick-radar.
- Engage networks of closely-related diseases but clarify differences in risk. Pre-existing networks of disease-specific community actors can be used to engage with new, closely-related diseases. For example, the extensive community-based network relating to lyme borreliosis (e.g. National Green Lyme Working Group) was an effective platform for channelling information and obtaining additional resources for TBE preparedness and response. However, the differing risk expectations associated with various disease histories may prove challenging.
- Integrate community engagement advice in preparedness planning, including disease outbreak guidelines. Community engagement guidance may be desirable in the case of zoonosis where inter-sectoral coordination is complex. Without guidance, relevant community level partners may be left out of the process, increasing the risk of miscommunication and counterproductive actions, and losing out on a preparedness and response resource.
- Invest in trust building with community-partners that are mistrustful by focusing on win-win solutions, sincerity and strategic patience. The development of trust and the cooling down of adversary relationships between health authorities and lyme borreliosis patient organisations was the result of long-term discussions, patience and the recognition that there were shared goals. The resulting patient synergies might be the key to success in public prevention programmes. However, there are limits to patient involvement as regards decisions on the funding of basic research which falls outside the patient agenda.
- Engage with commercial initiatives as opportunities for public engagement while actively ensuring that communication is accurate, both to the public and among the parties involved. While commercial partners can provide access to public education channels, there is a general suspicion which may not always be effective for engagement. An open, yet critical engagement is needed to avoid the spread of simplistic ideas or information. These networks should be used positively for public preparedness.

Communication

- Continue to support and invest in the maintenance of cross-sectoral, community-based platforms. Community-based disease networks provide excellent resources for the coordination of preparedness public education campaigns. For example, the annual 'Week of the Tick' campaign is organised by a coalition of cross-sectional stakeholders and is an excellent way to reach many more stakeholders than the authorities could do by themselves.
- Continue to engage stakeholders that were involved during early detection throughout all subsequent phases of the response. The request to keep information about TBE virus in deer restricted internally to green partners was followed by a public media announcement of a human TBE case without early notification to the same partners. This caused frustration among the green partners who had tried to manage restricted dissemination and led to a breakdown in trust.

[19] Federal Emergency Management Agency (2011) *A whole community approach to emergency management: principles, themes, and pathways for action*. FDOC 104-008-1. Washington (DC): Federal Emergency Management Agency.

- Monitor human resource capacities with respect to local media outreach when uncertainty is high. The expectation that local municipal health services are able to manage local media attention ignores the impact of timing and the potential of a media hype which may overwhelm local capacity.
- Support transparency and communication of ongoing processes (e.g. research progress or decision-making trajectories) even without final conclusions or decisions. While it is crucial to communicate results and decisions only after careful review, keeping the public informed of the quality and methodologies of ongoing processes builds trust.
- Invest in communicative capacity in the central health and regional authorities to provide an evidence-based voice in public discourse, in close collaboration with community-based partners. A key role for coordinating authorities is to be a neutral arbiter and to put facts into the public domain. The national coordinating body (RIVM) was seen as the only partner able to fill the role of fact checker in the national public domain. The Municipal Health Service may need supportive capacity, depending on competing demands.

Promoting inter-sectoral collaboration and synergies between the authorities

- Conduct a preliminary, comprehensive stakeholder analysis of relevant inter-sectoral partners. Emerging zoonotic disease requires a repositioning of the typical (standardised) stakeholder engagement by coordinating authorities. These new stakeholders mean extra investment in coordination and decision making regarding the extent of engagement.
- Carefully and in a timely manner explain the public health decision-making process to all stakeholders involved in the implementation phase. Engagement of inter-sectoral community partners will encourage questions about the balancing of commercial and/or agricultural risk against human health risks. On the one hand, there is a rationale for keeping decision-making medically focused during coordination and response. On the other hand, this runs the risk of excluding inter-sectoral, professional stakeholders who could judge the appropriateness of health actions in other contexts, facilitate timely communication in other networks, develop understanding of the organisation of the emergency health response, and avoid counterproductive measures across sectors.
- Continuously invest in ministerial coordination and negotiation by building collaborative capacity, creating win-win scenarios, and benefitting from positive experience during previous responses. Coordination between different ministries is important for zoonoses. However, coordination is slow and difficult and inter-sectoral responses have been varied and challenging - e.g. Q-fever in the Netherlands.
- Develop inter-sectoral workflow charts and support ‘One Health’ platform development. Unfamiliarity with different domains means that if people do not actually know each other they will not be encouraged to trust each other. Insight into the linkages between each other’s processes is helpful for partners to learn how their work is connected with that of ‘others’. The ‘One Health’ approach actively pursues such synergy, and is promising.

Other important lessons learned that do not directly relate to synergies

- Use community brokers to reach vulnerable populations. Vulnerable populations (e.g. asylum seekers, hikers, foreign tourists, pet owners, scouting groups, schools, day-care, garden owners, or volunteers working with community partners) may include community members reached only through specific brokers in the network. With respect to volunteers, one suggestion is to involve accredited occupational health services to ensure that appropriate tick-borne disease information and preventive structures are available on an annual basis.
- Conduct post-incident evaluations. Efforts to conduct formal evaluations after a public health incident can ensure that institutional memories are sustained and that lessons learned are remembered in the longer term. Work with different authorities to share experiences and establish regular post-event evaluations.

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Annex1. Respondents

Category	Type[1]	Institute represented	Name	Professional title
National	KI	Ministry of Health, Welfare and Sport (VWS)	Stephanie Wiessenhaan	Coordinating policy advisor, Zoonoses
National	KI	Ministry of Health, Welfare and Sport (VWS)	Yvonne de Nas	Senior policy advisor, Infectious Diseases
National	KI	RIVM Communication	Kevin Kosterman	Communication advisor
National	KI	RIVM EPI	Agnetha Hofhuis	Infectious disease epidemiologist
National	KI	RIVM EPI	Kees van den Wijngaard	Senior researcher
National	KI	RIVM IDS	Kristin Kremer	Interim Head of the Department, Perinatal Screening and Bacterial Serology
National	KI	RIVM LCI	Corien Swaan	Head Department for Prevention and Control
National	KI	RIVM LCI	Dorothee Roβkamp	Senior policy advisor, Preparedness
National	KI	RIVM LCI	Desiree Beaujean	Head of Department, Guideline Development
National	KI	RIVM LCI	Hans Lobach	Head Regie & member of the Dutch Lyme Disease Expertise Centre
National	KI	RIVM Z&O	Hein Sprong	Research coordinator & scientist
Regional	KI	Amsterdam Academic Medical Center (AMC)	Joppe Hovius	Professor of Medicine, Internist, AMC Lyme Center
Regional	KI	Municipal Health Service Twente (GGD Twente)	Karel Soethoudt	Medical doctor, Senior consultant, Communicable Disease Control
Regional	KI	Municipal Health Service Utrecht (GGD Region Utrecht)	Diederik Brandwagt	Junior consultant, Infectious Disease Control
Regional	KI	Municipal Health Service Utrecht (GGD Regio Utrecht)	Ans van Lier	Senior consultant, Communicable Disease Control
Regional	KI	Agrarian Personnel Health Service (STIGAS)	Mirjam de Groot	Prevention advisor, Green Sector
Regional	KI	Wageningen University and Research Central Veterinary Institute	Hendrik-Jan Roest	Head of department, Bacteriology and Epidemiology
Communiy	KI	Dutch Association of Lyme Patients (NVLP)	Gert van Dijk	Former Chair of Board
Community	KI	Independent	Lizi Slok	General practitioner
Community	FGD	Association Het Edelhert & Dutch Wildlife Health Centre	Margriet Montizaan	Hunter, communication advisor, volunteer
Community	FGD	Dutch Tourist Camping Club (NTKC)	Albert Fien	Head of Board
Community	FGD	Goois Nature Reserve	Johan Griffioen	Cattle and sheep farmer
Community	FGD	Groenklus	Jan Groot	Owner, Maintenance professional, Forester
Community	KI	Landschapsbeheer Drenthe & FNV	André Efftink	Tree and landscape specialist
Community	FGD	Municipality of Amersfoort	Marjolijn Hinkofer	Advisor, Living Environment & Public Space
Community	FGD	Municipality of Amersfoort	Aart van Egteren	Advisor, Living Environment & Public Space
Community	KI	Scouting Netherlands	Nadir Baali	National Council Scouting and local scouting board member. Lyme patient
Community	FGD	Forestry Service (SBB)	Rein Zwaan	Team leader, Utrecht region
Community	FGD	Forestry Service Salland/Twente	Ton Klomphaar	Forestry monitoring and ecological adviser
Community	KI	Tickbite Patient Organisation (Tekenbeetziekte)	Diana Uitdenbogerd	Lyme patient representative
Community	FGD	Utrecht Natuurlijk City Garden Overvecht	Rudi van Bokhoven	Location coordinator
Community	FGD	Utrecht Natuurlijk Koppelsteede Children's Farm and Park	Tamira de Pijper	Location coordinator

[1] KI = Key informant interview, FGD = Focus group discussion

Annex 2. Documents identified

(for media documents, see Annex 8)

Literature search was done using the keywords 'Lyme', 'LB', 'TBE', 'Tick-borne Encephalitis' in both Dutch and English using Google Scholar. A few documents were provided by the RIVM directly, and others indirectly through the website: https://www.rivm.nl/Onderwerpen/T/Tekenbeten_en_lyme and https://www.rivm.nl/Onderwerpen/T/Tekenencefalitis.

Author	Year	Title	Source
AJ en LI.	Unknown	Sociale kaart LCI preparedness. Versie 4: 25614. Vastgesteld in IBO dd. 161214WHO	RIVM
Albu et al.	2014	Annual epidemiological report 2014 – emerging and vector-borne diseases.	European Centre for Disease Prevention and Control
AMC, NVLP, Radboudumc,RIVM	2017	Nederlands Lymeziekte-expertisecentrum: Beleidsplan 2017-2020	DOI: 10.21945/Nederlands-Lymeziekte-expertisecentrum
Beaujean	2013	Study on public perceptions and protective behaviors regarding Lyme disease among the general public in the Netherlands	BMC Public Health 225
Beaujean et al.	2013	Using Risk Group Profiles as a Lightweight Qualitative Approach for Intervention Development: An Example of Prevention of Tick Bites and Lyme Disease	JMIR research protocols, 2(2) [e45]
Beaujean et al.	2014	Wat weten, denken en vinden Nederlandse schoolkinderen van teken en lymeziekte?	Infectieziekten Bulletin (25)9:255-257
Brandwagt et al.	2017	Tekenencefalitis, een nieuwe ziekte in Nederland?	Infectieziekten Bulletin (28)4:116-120
Crutzen	2014	Preventive behaviours regarding tick bites	BMJ ;348:g231 doi: 10.1136/bmj.g231
De Graaf et al.	2016	First human case of tick-borne encephalitis virus infection acquired in the Netherlands, July 2016. Eurosurveillance, 21(33):pii=30318.	
De Graaf et al.	2016	First human case of tick-borne encephalitis virus infection acquired in the Netherlands, July 2016	Eurosurveillance,21(33):pii=30318
De Groot	2011	Teken, tekenbeten en de ziekte van Lyme bij werkenden in de groene sector	Infectieziekten Bulletin (22)2:58-60
de Jong & Wiessenhaan	2017	Beleidshandboek crisisbesluitvorming zoönose	Infectieziekten Bulletin (28)4:113-115
De Vos et al.	Unknown	Emerging zoonoses in relation to the changing socio-economic environment	Wageningen University & Research
Den Oudendammer & Broerse	2017	Lyme disease in the Dutch policy context: patient consultation in government research agenda setting	Science and Public Policy, 1–14
European Parliament	2013	DECISION No 1082/2013/EU OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 22 October 2013 on serious cross-border threats to health and repealing Decision No 2119/98/EC	Official Journal of the European Union L 293/1
Fonville et al.	2013	Blootstelling aan Borrelia miyamotoi door tekenbeten	Infectieziekten Bulletin (24)10:314-317
Gassner	2017	Overview communication tools, work-groups, stakeholders and literature in the field of tick bites and Lyme borreliosis in the Netherlands	RIVM
Gassner et al.	2010	Geographic and temporal variations in population dynamics of Ixodes ricinus and associated borrelia infections in The Netherlands.	Vector-Borne Zoonotic Dis, 11:523–532.
Gassner, F.	2014	Vraag uit de praktijk: Tekenweetjes	Infectieziekten Bulletin (25)4:119-120
Harms et al.	2014	Tekenradar.nl, een webplatform over tekenbeten en de ziekte van Lyme	Infectieziekten Bulletin (25)7:204-206
Heinz et al.	2013	Vaccination and Tick-borne Encephalitis, Central Europe	Emerging Infectious Diseases 19(1):69-76
Hira & Rockx	2017	Human Tick-Borne Encephalitis, the Netherlands	Emerging Infectious Diseases 23(1):169
Hofhuis & Pelt	Unkown	Inventarisatie van de haalbaarheid en wenselijkheid van een meldingsplicht voor Lyme-borreliose	RIVM CIb
Hofhuis et al.	2017	Tekenencefalitis in Nederland: een studie naar blootstelling aan tekenencefalitis (TBE) virus onder mensen met een beroepsmatig hoog risico op tekenbeten in Nederland	RIVM CIb
Jahfari et al	2017	Tick-Borne Encephalitis Virus in Ticks and Roe Deer, the Netherlands	Emerging Infectious Diseases, 23(6), 1028-1030
Kaaijk et al.	2016	Vaccineren tegen de ziekte van Lyme: Hoe ver zijn we?	Infectieziekten Bulletin (27)7:198-201

Author	Year	Title	Source
Kuiper et al.	1991	Lyme borreliosis in Dutch forestry workers	Journal of Infection (I99I) z3, 279-286
Maat & Konings	2010	Teek it or leave it? Onderzoek van GGD West-Brabant naar preventieve maatregelen tegen tekenbeten	Infectieziekten Bulletin (21)7:221-223
Medlock et al.	2013	Driving forces for changes in geographical distribution of Ixodes ricinus ticks in Europe	Parasites & Vectors 6:1
Mulder et al.	2013	High Risk of Tick Bites in Dutch Gardens	Vector-Born and Zoonotic Diseases 13(2)
Ostfeld et al.	2015	Climate change and Ixodes tick-borne diseases of humans	Phil. Trans. R. Soc. B 370:20140051
Randolph	2010	Human activities predominate in determining changing incidence of tick-borne encephalitis in Europe	Eurosurveillance, 15(27):pii=19606
Reusken	2011	Case report: Tick-borne encephalitis in two Dutch travellers returning from Austria, Netherlands, July and August 2011	Eurosurveillance, 16(44):pii=20003
RIVM	2016	Afstemmingsoverleg TBE Stakeholderanalyse, 26 oktober 2016 12.30-14.00 uur	RIVM-LCI
RIVM	2014	Generiek draaiboek infectieziektebestrijding	RIVM
RIVM	2013	Lymeziekte Richtlijn	RIVM LCI
RIVM	2010	Tekenencefalitis Richtlijn	RIVM LCI
RIVM	2014	Voorlichtingscampagne RIVM over teken en lyme gaat weer van start	Infectieziekten Bulletin (25)3:88
Sedda et al.	2014	Risk assessment of vector-borne diseases for public health governance	Public Health 128:1049-1058
Sprong & Braks	2016	Introduction: choosing a One Health approach for the control of Lyme borreliosis	Ecology and prevention of Lyme borreliosis (Book)
Sprong et al.	2011	Tekenoverdraagbare aandoeningen: meer (dan) Lyme?	Infectieziekten Bulletin (22)2:56-57
Stanek & Strle	2008	Lyme Disease-European Perspective	Infect Dis Clin N Am 22:327–339
Van den Berg	2012	Projectverslag Risico op zoönosen in de provincie Utrecht. Een samenwerkingsproject met ketenpartners.	GGD-Midden Nederland
Van den Wijngaard et al.	2006	Is tickborne encefalitis (TBE) een dreiging voor Nederland?	Infectieziekten Bulletin (17)12:417-419
Van der Giesen & Kramer	2016	Signaleringsoverleg Zoönosen viert vijfjarig jubileum	Tijdschrift voor Diergeneeskunde 6:48-49
Van der Poel	2005	Attempt to Detect Evidence for Tick-Borne Encephalitis Virus in Ticks and Mammalian Wildlife in the Netherlands	Vector-Borne And Zoonotic Diseases, 5(1)
Van Hoeven et al.	2013	Kennis over teken en Lyme op basisscholen toegenomen, maar screening kan beter	Infectieziekten Bulletin (24)10:328-329
Van Velsen et al.	2012	Via risicoprofielen naar preventie op maat: teken en de ziekte van Lyme	Infectieziekten Bulletin (23)9:306-311
Van Velsen et al.	2015	Developing requirements for a mobile app to support citizens in dealing with ticks and tick bites via end-user profiling	Health Informatics Journal 21(1) 24–35
Weststrate et al.	2017	Increasing evidence of tick-borne encephalitis (TBE) virus transmission, the Netherlands, June 2016	Eurosurveillance 2017;22(11):pii=30482
Wiessing et al.	1991	Lyme-Borreliose by uitvoerend personeel van staatsbosbeheer en aandachtspunten voor epidemiologisch vervolgondezoek	RIVM

Annex 3. Interview and focus group discussion questions

Two draft sets of questions were produced: one for interviews with experts, and one for focus group discussions with community representatives; many questions are the same for both groups, allowing us to examine given issues from these different perspectives. The questions had only minor differences in emphasis and wording. The questions were shared with the Dutch focal point for input and further discussion. The institutional versions appear below.

Part 1. Mapping the different stakeholders

1. Please tell us how you and the institution you work for have been or are involved with TBE/lyme borreliosis.
2. Could you map out on a piece of paper the different stakeholders or groups that have been or are involved with preparing for and/or responding to TBE/lyme borreliosis. Which of these would you define as coming from the community, and which would you define as 'authorities'? Do you think there are any stakeholders – institutional or from the community – who are missing from this map who should be included in order to ensure a better response?

Part 2. Issues arising during each of the three phases of the public health event

Anticipation phase (prior to the event)

3. To what extent were there any public health preparedness exercises, consultations, or training activities involving both the community and the authorities prior to this case? Please describe these. Do you consider these activities to have been sufficient? If not, what could have been done in addition?
4. In general, do you think that the community trusted the public health & scientific authorities in this area prior to the event? Had there been any specific events (such as other disease outbreaks) that promoted or undermined trust? Details.

Response phase (during the event)

5. Were there sufficient numbers of dedicated professional staff in the area, able to respond to the case? Were there any problems, for example with funding, that may have limited the response?
6. Was there any official guidance for the authorities on how to engage with the community in this case(s)? What form did this guidance take?
7. Were the key actors in the community clearly identified and available when the case(s) first appeared? To what extent was there clarity about who was expected to do what?
8. What were people's sources of information about the event (i.e. press and social media etc.)? How informative, coherent and consistent were these sources of information? Were there any issues that you think people felt they needed to know more about?
9. How was the communication and coordination between the community and the authorities during the response to this event [i.e. shared/democratic/top-down?] Were there any aspects that could have been improved?
10. To what extent did different parts of these community trust and cooperate with each other during the response to this event? Examples?
11. Were there any groups in the community who, for any reason, were excluded from the response? Details.
12. Were there any hard-to-reach or vulnerable groups? What efforts, if any, were made to reach out to them, by whom, and what lessons could be learned from this?

Recovery phase (after the event/outbreak – or, in the case of endemic, seasonal lyme borreliosis, after a season)

13. Was there any sort of post-case review of the event, including with reference to community-institutional collaboration? If so, what form did it take, who was involved, and what was the outcome?
14. How much awareness do you think there currently is in the community about this event? Do you think that lessons have been learned by the community regarding prevention and response practices for future events of this nature?

Part 3. Overview

15. Overall, how would you describe (i) the community response and (ii) the official response to the event? Were you satisfied, or do you think some aspects could have been improved?
16. In general, how do you feel the community and the authorities collaborated during this event? What would you say was the most successful aspect of any collaboration? What were the main challenges faced in the collaboration process, and what efforts, if any, were made to overcome these?
17. What do you think are the main lessons learned from this event, in terms of community-institutional collaboration and preparing for future public health emergencies or events?
18. Is there anything else you would like to add?

Annex 4. Ethical consent form

There were two versions of the informed consent form, one for the interviews (with officials from the health/non-health sectors), and one for the focus groups (with the community). They differed slightly in wording. Both were translated into Dutch by a native speaker.

1. Officials from the health/non-health sectors – Informed consent form

Study title: Enablers and barriers for community and institutional public health emergency preparedness synergies

As part of the process of increasing inter-sectoral preparedness for serious cross-border public health threats, the European Centre for Disease Prevention and Control (ECDC) has initiated a case study project to investigate the synergies between communities affected by serious public health threats and the institutions (both health- and non-health-related) that are mandated to prepare for and respond to them.

Two EU countries have been selected for inclusion in the case study, in agreement with ECDC and the countries concerned: Spain and the Netherlands. Both of these countries are increasingly affected by serious tick-borne diseases, due to climate and other environmental changes. These diseases will be the focus of the work, which will seek to document the perspectives and experiences of key actors with respect to them in (i) the health sector, (ii) relevant non-health sectors, and (iii) in the affected communities.

You have been identified as a representative of one of the official institutional informant categories that are considered as being critical in preventing, preparing for and/or responding to a tick-borne disease outbreak. In addition to the health sector, our official institutional informants come from agriculture, animal health, tourism, and forestry.

Your participation in the interview is entirely voluntary, and if you agree to take part, you are free to change your mind or withdraw at any time without consequences. If you agree to take part in an interview, any processing of your personal data will comply with Regulation 45/2001[20] and Swedish national law. ECDC is the data controller of this processing operation, and the data is collected and stored by the University of Umeå on its behalf, in its role as processor of the data. The interview will be conducted by two social scientists from Umeå University in Sweden, who are working with ECDC on the project. One member of the interview team will conduct the interview with you, while the other will take notes (either by hand, or on a laptop computer). We will ask if you are comfortable for us to record the interview, so that we can subsequently check and confirm our understanding of what was said. At no stage will anybody outside the interview team have access to the recording, and it will be deleted from our computer/s once the analysis of the interview is complete. The recording of your interview will be copied onto a memory stick and stored in a locked and secure safe on the University premises. After 5 years, the file will be permanently deleted. If you prefer for us not to record the interview, of course we will fully respect your wish, and we will rely instead on the notes taken during the interview.

With your agreement, we may want to quote some of what you say in the report that we will be writing, but we will do so in a way that ensures that it cannot be ascribed to you. Also, with your agreement, we may want to include your name and institutional affiliation in an Annex that lists the informants who have contributed to this case study project.

As a data subject, you have the right of access and rectification of your personal data. Feel free to ask any questions you may have about the interview or the processing of your personal data. If you have questions after the interview is over, please contact Svetla Tsolova at ECDC (svetla.tsolova@ecdc.europa.eu).

Please check 'yes' or 'no' by each of the following statements, sign and date the document in the space provided below.

	Yes	No
I agree to having the interview recorded (note that if you prefer for us not to record the interview, of course we will fully respect your wish, and we will rely instead on the notes taken during the interview).		
I agree to having my words used as quotes in the final report, and I understand that my words will be anonymized so that it will not be possible to ascribe any of my comments to me.		
I agree to having my name and institution included in an Annex at the end of the final report that lists the informants who have contributed to this case study project.		

Signature: _____

Name (in CAPITALS): _____

Date: _____

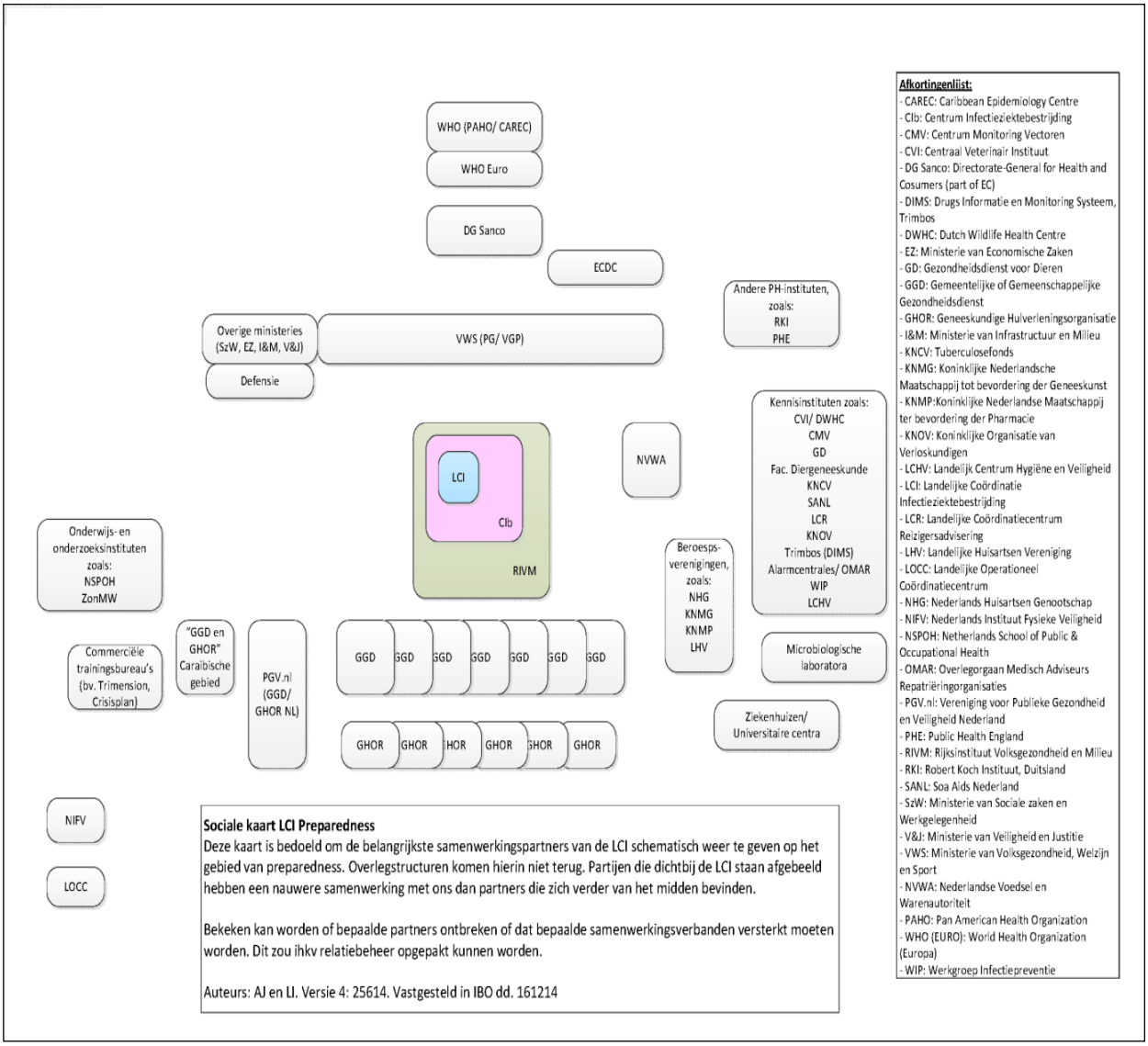
[20] Regulation (EC) No 45/2001 of the European Parliament and of the Council of 18 December 2000 on the protection of individuals with regard to the processing of personal data by the Community institutions and bodies and on the free movement of such data

Annex 5. List of codes and thematic classification

Code	Theme classification
AID (& RIVM lab)	Synergies authority - community Lyme
ARBO	Synergies authority - community Lyme
Bias in patient representation	Challenges
Burgerinititatief	Synergies authority - community Lyme
Camping association	Synergies authority - community Lyme
Camping initiative	Community initiative
Citizenscience – Tekenradar	Synergies authority - community TBE &lyme
Clinical focus	Challenges
Communication	Challenges
Communication and information	Communication and Media
Communication with patients	Aspirations for synergy in future
Cross border	Synergies inter-sectoral
Dealing with different stakeholder interests	Challenges
Definition health in environment law	Challenges
Diagnostic uncertainty	Challenges
Dissemination	Challenges
Distrust	Challenges
Division responsibilities health in nature	Challenges
Exclusion nature partners in coordination	Challenges
Funding	Challenges
Gezondheidsdienst voor Dieren	Synergies authority - community TBE
GGD & Nature	Synergies inter-sectoral
Green cloud	Challenges
Guidelines	Guidelines
Hard to reach & Vulnerable groups	Challenges
Hunters	Synergies authority - community TBE
ILADS	Synergy community to private
Lack of post-case evaluation	Challenges
Landelijke Groene Lyme Werkgroep	Synergies authority - community Lyme
Lyme & generic infrastructure	Relation TBE and lyme infrastructure
Lyme Disease Awareness Month	Synergies authority - community Lyme
Mandated role of authority to inform	Communication and Media
Media attention	Communication and Media
Media documentaries	Communication and Media
Media training	Communication and Media
Multidisciplinaire guideline Arbeid & Lyme	Guidelines
Nature owners now	Synergies authority - community TBE &lyme
Nature owners future	Aspirations for synergy in future
Nature partners	Synergies inter-sectoral
Nederlands Lyme Expertise Centrum	Synergies authority - community Lyme
Nederlandse Verening voor Lymepatienten	Synergies authority - community Lyme
Occupational sector & VWS	Synergies inter-sectoral
One Health	Synergies inter-sectoral
Ontwikkelings Maatschappij Flevoland	Synergy community to private
Patient organisation relationship to TBE	Relation TBE and lyme infrastructure

Code	Theme classification
Perceived misrecognition lyme	Challenges
PIN (online course lyme for GP)	Aspirations for synergy in future
Power of patient organisation	Synergies authority - community Lyme
Prevention versus response	Challenges
Previous models and analogies	Challenges
Privatisation of Nature Management	Challenges
School	Synergies authority - community Lyme
Schools & Scouting (children)	Aspirations for synergy in future
Scouting initiative	Community initiative
Shooting the messenger	Synergies inter-sectoral
Signaleringsoverleg (SOZ)	Synergies authority - community TBE
Social media monitoring	Communication and Media
Spatial misalignment	Challenges
Stakeholder analysis research RIVM	Synergies authority - community Lyme
Surveillance complacency	Challenges
TBE – outbreak	Synergies inter-sectoral
Teek pak 'm beet	Synergies authority - community Lyme
Thuisarts.nl	Communication and Media
Vaccination research and ecology	Aspirations for synergy in future
Veterinary & health - win	Synergies authority - community TBE &lyme
Week van de Teek	Synergies authority - community Lyme
yearly knowledge exchange day	Synergies authority - community TBE &lyme
ZonMw	Synergies authority - community Lyme
Zorgplicht (Duty to care)	Challenges

Annex 6. Social map of RIVM-LCI preparedness (source RIVM-LCI)



Annex 7. Stakeholder analysis TBE

Stakeholder	What coordination needs from stakeholder	What stakeholders needs from coordination
Risk groups		
Recreational actors		
Tourists		
Military		
Forestry, green and fieldworkers*	Percentage of people with tick bites and how many of these TBE to provide correct measures & advise Information about behaviour and basic knowledge about prevention for improvement Information collection regarding actual use of prevention measures (STIGAS and Forestry Service)	Practical prevention guide Practical information about when to consult a general practitioner Vaccination advice Risk assessment in relation to proportionality of measure
Scouting		
Medical care providers / medical stakeholders		
Municipal Health Services	Information about patients (surveys/signals) More public communication, both active and passive Advise municipalities of TBE risks	Offer surveys for patients Ready-to-go public communication messages Create more alertness
Hospitals		
General Practitioners	Disseminate information to risk groups (thuisarts.nl, screens, etc.) Alertness among people without frightening them	Ready-to-go information on disease and diagnosis Create more alertness
Specialists (neurologists, infectious disease experts)	Recognize and signal TBE as long as it is not mandatory to inform RIVM Offer surveys to patients	Information about signalling and diagnostics TBE Offers (basic) information for contacts/families patient Guidelines in collaboration with professional associations
Animal doctors	Inform animal owners of animals who are outside. Collect ticks for research	Ready-to-go information for pet owners Information if animals can be off-leash/free
Laboratories (medical microbiology)	Provide access to specialists Notifications	Low-threshold accessibility for colleagues Lot of contact with other clinicians and colleagues
Pharmaceutical companies (vaccination)		
Agrarian Personnel Health Service (STIGAS)		
Military occupational health		
Government / politicians / media		
Ministry of Health, Wellbeing, Sport		
(Social) media	Provision of proportionally correct information to target audience	Ready-made public information Practical information on when to consult a physician

Stakeholder	What coordination needs from stakeholder	What stakeholders needs from coordination
Knowledge institutes / associations		
National Institute for Public Health and Environment (RIVM)		
Dutch Wildlife Health Centre (DWHC)		
Naturemanagers, owners, and associations		
DLO (Alterra)		
Wageningen University Research Centre		
Dutch Association of Lyme Patients (NVLP)	• Signals, polling of emotions and frequently asked questions. • Provision of correct information to patients	• Well supported information (specialized information relative to the general public)
Tickbite Patient Organisation (Tekenbeetziekte)		
Producers of tick prevention materials (Rovince, vaccines)		
Association Forest & Nature Owners (VBNE)*		
Professional Journals	• Provision of proportionally correct information to target audience	
Sallandse Region (nature conservation, private property owners)	• Collaboration in research on ticks	• Preliminary information provision (before media0 • Ready-made information for public and staff • Engagement throughout entire process and offer of privilege to receive information first
Utrecht Landscape	• Same as Sallandse Region	• Same as Sallandse Region
Royal Dutch Hunting Association (KNJV), farmers and property owners	• Collaboration in research • Building and keeping trust	• Early signalling to be able to anticipate • Ready-made information • Applicable instructions for research sampling • Feedback on results
Regional zoonotic networks		
Network of green agencies	• Informing members, • Monitoring if prevention measures are being followed and how many people are bitten by ticks.	• Ready-made public information • Practical information when to consult a physician

Source: RIVM-LCI

* Multiple organisations: Forestry service, nature conservation organisation (Natuurmonumenten), Federation of private properties, 12Landscapes, Ministry of Defence.

Annex 8. Summary of media analysis

Before TBE human case

Volkskrant 11-5-2010 Ticks, lyme TBE very short

Dokterdokter.nl 5-4-2016: Ticks, TBE en Frühsommer-meningoencefalitis (FSME), information folder Tekenbeet of GGD. Symptoms, when tot he GP? Prevention, vaccination

De Utrechts heuvelrug 26-6-2016 : Information about ticks and lyme

After TBE human case

Linda Nieuws 21-7-2016: referred to RIVM, factual and short and mentioned the RIVM. Emphasis was placed upon the low risk to get encephalitis from ticks. The RIVM research during which the virus was found with deer in de Sallandse Heuvelrug is briefly mentioned.

Metronieuws 21-7-2016: emphasis on first human TBE case in Netherlands reported by RIVM. Patient was bitten by tick during walk at the Utrechtse Heuvelrug. Symptoms are described and the small chance of encephalitis. Also Brief mentioning of Lyme

NU.nl 21-7-2016: First patient ill in NL. Reported by RIVM. Comparison with Lyme: decreased risk of becoming ill. Symptoms mentioned.

Utrecht Nieuws 21-7-2016: Virus exist in North, Middle and East Europe, amongst others in Germany and Austria.

Medisch Contact 1-7-2017: first TBEV in Sallandse Heuvelrug, no patients yet. RIVM, incubation time, symptoms, possibility of encephalitis, origin of the virus. No reason according to RIVM for vaccination

Blik op nieuws 21-7-2016: First human TBE patient, RIVM reference, origin, symptoms, GPs need to be alert, prevention for tick bites, TBE in ticks

Later

Telegraaf (Sterkliniek Dierenartsen Den Helder): New tick-borne virus. Comparison with Lyme: higher risk of getting ill. Reference to RIVM. Be alert for ticks. Symptoms

WUR 28-7-2016: Research to check animals for TBE. TBE origin, symptoms, prevention against ticks, GPs need to be alert, link to RIVM.

NOS 14-8-2016: RIVM, one human case of TBE, tick, prevention, origin, questions for RIVM, research by RIVM and CVI (central veterinary institute and WUR (Wageningen). Vaccination exist, but only in certain countries and areas needed. Risk of Lyme versus risk for TBE: Forestry service no questions, hikers aware of ticks already. Tick prevention, referral to RIVM.

NRC 31-3-2017: Lyme, TBE, ticks, comparison risks, first two human cases in NL, RIVM research with AMC, preventive measures for hikers and land owners (use of signs, mowing the grass besides the paths), symptoms, complaints go to GP.

AD 30-6-2017: Risk compared to Lyme, reference to RIVM. TBEV signalled in Sallandse Heuvelrug detected in deer. No human cases yet. Most people infected with TBE no symptoms, some people do. Discussion of the readers underneath about GPs not taking tick bites and Lyme serious

Vacciweb: TBE, risk, risk people (hikers, scouting, campers, ticks, prevention, vaccination, origin location of TBE

VBNE: TBE in humans or (FSME). Origin, prevention of ticks, reference to RIVM and research in deer, emphasis on those working in green sector, comparison TBE and Lyme, reference to website RIVM

Nieuws.nl: Week van de teek, ticks, season, Lyme and TBE2 human TBE cases. Gelerse valley Lyme, TBE, prevention, origin, reference to RIVM

MMI laboratorium: reference to RIVM and labinf@ct: TBE in humans, origin, diagnositcs, symptoms.

Vaccination information on travel website: information about TBE

GGD: Vaccination website, reference to RIVM and information film (about ticks, how you get it, symptoms, how you remove it, tick bite, report where in your body and when tick has bitten you and keep an eye on it for three months go to GP with complaints) information about ticks prevention, where TBE is from, raw milk

GGD: tick prevention

Lyme related articles in popular fora

Linda Walking for Lyme in 19-2-2016. About marathon for Lyme funding and chronic Lyme treatment

Scouting forum: About petition for antibiotics for Lyme. Debate: considered panic making or fight against the GP who does not take it seriously.

Website scouting: Prevention of tick, information about Lyme

Annex 9. Name translation of organisations in participatory stakeholder mapping

English translation	Dutch original name (abbreviation)
Academic Medical Centers	Academische Medische Centra
Agrarian Personnel Health Service	Stichting Gezondheidszorg Agrarische Sectoren (STIGAS)
AMC Lyme Research Centre	Amsterdams Multidisciplinair Lyme borreliose Centrum
AMC Molecular Medicine	Centrum voor Experimentele en Moleculaire Geneeskunde (CEMM)
Amsterdam Med Center	Amsterdam Medisch Centrum (AMC)
Animal Health Laboratory Service	Gezondheidsdienst voor Dieren (GD)
Association of Dutch Family Medicine	Nederlands Huisartsen Genootschap (NHG)
Association Forest & Nature Owners	Vereniging van Bos- en Natuurterreineigenaren (VBNE)
Association of Children's Farm	Vereniging Samenwerkende Kinderboerderijen Nederland (vSKBN)
Association of Family Medicine	Huisartsen vereniging
Association of Forestry	Algemene Vereniging Inlands Hout (AVIH)
Association of Medical Practitioners	Landelijke Huisartsen Vereniging (LHV)
Asylum Seekers	Asielzoekers
Children's Farms	Vrijwillige Kinderboerderijen
Christian Union	Christelijk Nationaal Vakverbond (CNV)
City Farm Utrecht (Koppelsteede)	Utrecht Natuurlijk Stadsboerderij Koppelsteede
City Garden Utrecht (Overvecht)	Utrecht Natuurlijk Stadstuin Overvecht
Defense Department	Defensie
Dutch Association of Lyme Patients	Nederlandse Vereniging van Lyme Patienten (NVLP)
Dutch Food Safety Administration	Nederlandse Voedsel- en Warenautoriteit (NVWA)
Dutch Green Tourism Club	Nederlandse Toeristen Kampeer Club (NTKC)
Dutch Hunting Dog Association	Nederlandse Jachthonden Vereniging
Dutch Lyme Expertise Centre	Nederlands Lymeziekte-expertisecentrum (NLE)
Dutch Wildlife Health Centre	Dutch Wildlife Health Centre (DWHC)
Elderly Care Facitity	Verzorgingstehuis
EU Health Security Committee	Europese Unie Health Security Committee (EU HSC)
Family Medicine Posts	Huisartsenposten (HAP)
Family Medicine Practitioners	Huisartsen
Federal Union	Federatie Nederlandse Vakvereniging Agrarisch (FNV)
First Aid Professionals	EHBO
Flevoland Development Association	Ontwikkelingsmaatschappij Flevoland
Forestry Service	Staatsbosbeheer (SBB)
Gardeners	Moestuinierders
Gelders Landscape	Gelders Landschap
National Green Lyme Working Group	Groene Lyme Werk Groep (GLWG)
Healthcare Network Middle Region	Ambulante Zorggroep Midden-Nederland (AZMN)
Herders Association	Het Schaap
Higher Prof Education Dronten	Aeres Hogeschool Dronten
Hospital	Regionaal Ziekenhuis
Hunting Organisation Edelhert	Vereniging het Edelhert
Hunting Organisation Reewild	Vereniging het Reewild
Knowledge Centre Occupational Health	Kenniscentrum Infectieziekten en arbeid (KIZA)
Landscape Organisation	Landschappen Nederland
Legal representatives (Beer)	Beer Advocaten
Med Emergency Mgmt National	GGD GHOR Nederland
Med Emergency Mgmt Regio	Geneeskundige Hulpverleningsorganisatie in de regio (GHOR)
Medical Government Council	Gezondheidsraad
Medical Microbiology Laboratories	Medisch Microbiologisch Laboratoria (MML)
Medical Practitioners (first line)	Eerstelijnszorg
Ministry Agricultre, Fisheries, Nature	Ministerie van Landbouw Natuur Visserij (LNV)
Ministry of Economic Affairs	Ministerie van Economische Zaken
Ministry of Health, Wellbeing, Sport	Ministerie van Volksgezondheid, Welzijn en Sport (VWS)

English translation	Dutch original name (abbreviation)
Ministry of Infrastructure & Water	Ministerie van Infrastructuur en Waterstaat (IenW)
Ministry Social Issues & Employment	Ministerie van Sociale Zaken en Werkgelegenheid (SZW)
Municipal Health Service	Gemeentelijke Gezondheidsdienst (GGD)
Municipality	Gemeente
Nat. Park Utrecht Heuvelrug	Nationale Park Utrechtse Heuvelrug (NPUH)
National Science Foundation Lyme	Nederlandse organisatie voor gezondheidsonderzoek en zorginnovatie Programma Lyme (ZonMw)
Nature Conservation Organisation (Dutch Society for Nature Conservation)	Natuurmonumenten
Neighborhood	Buurtbewoners
NWVA Centre Monitoring Vectors	Centrum Monitoring Vectoren (CMV)
Occupational Health Collaboration	Samenwerkende Artsen- en Adviesorganisaties in de Gezondheidszorg (SAAG)
Occupational Health Practitioner	ARBO Bedrijfsarts
Occupational Health Union (Arbo Unie)	Arbo Unie
Parliament	Parlement
Patients	Patienten
Pharmacies	Apotheek
Private Biological Consultant (Gassner)	Gassner Biologisch Risico Advies
Private Laboratory (Innatos)	Innatos Laboratories BV
Private Nature Owners	Natuureigenaren
Provence	Provincie
Provincial Landscape Organisation	Stichting Noord-Hollands Landschap
Radboud University Medical Centre	Radboudumc
Rangers Middle Region	Buitengewoon Opsporingsambtenaren (BOA) Recreatie Midden-Nederland
Regional Fauna Management Unit	Faunabeheereenheden
Regional Game Management Unit	Wildbeheereenheden
Regional Medical Practitioners Group	Regionale Kringen
Regional Nature Conservation Gooi	Stichting Goois Natuurreservaat
RIVM-Centre Infection Control	RIVM Centrum Infectiebestrijding (CIb)
RIVM-CIb Centre for Diagnostics	RIVM-CIb Infectieziekteonderzoek, Diagnostiek en Screening (IDS)
RIVM-CIB Communication	RIVM-CIB Communicatie
RIVM-CIb Coordination Outbreak Control	RIVM-CIb Landelijk Coordinatiecentrum Infectieziektebestrijding (LCI)
RIVM-CIb Epidemiology	RIVM-CIb Epidemiologie en Surveillance van Infectieziekten (Epi)
RIVM-CIb Zoonotic & microbiology	RIVM-CIb Zoonosen en Omgevingsmicrobiologie
Royal Dutch Hunting Association	Koninklijke Nederlandse Jagersvereniging (KNJ)
Royal Landscapes	Kroondomeinen
Schools	Scholen
Scouting	Scouting Nederland
Scouting Local	Scouting Steenbergen
Societal Reintegration Projects	Reintegratieproject
Tickbite Patient Organisation	Stichting Tekenbeetziekten
Unemployment Services	Uitvoeringsinstituut Werknemersverzekeringen (UWV)
University of Utrecht	Universiteit Utrecht (UU)
University of Wageningen	Wageningen Universiteit and Research(WUR)
Utrecht Landscape Organisation	Utrechts landschap
Utrecht Platform OneHealth	Kennisnetwerk Zoönosen Midden Nederland
Veterinarians	Dierenartsen
Veterinary Medicine, Utrecht Univ.	Faculteit Diergeneeskunde Universiteit Utrecht, Institute for Risk Assessment (IRAS)
vSKBN Health Working Group	vSKBN Landelijke werkgroep gezondheid
Women's Groups	Vrouwengroepen
WUR Bioveterinary Research	Wageningen Bioveterinary Research (WBVR)
Youth Services	Jeudsgezondheidszorg (JGZ)

European Centre for Disease Prevention and Control (ECDC)

Address:
Gustav III:s boulevard 40, SE-169 73 Solna, Sweden

Tel. +46 858601000
Fax +46 858601001
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