TECHNICAL REPORT

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Abbreviations

AC	Autonomous Community
CCAES	Coordination Centre for Health Alerts and Emergencies, Spain
CCHF	Crimean-Congo haemorrhagic fever
CCHFV	Crimean-Congo haemorrhagic fever virus
CIb	Centre for Infectious Disease Control, Netherlands
ECDC	European Centre for Disease Prevention and Control
EEA	European Economic Area
EU	European Union
EVD	Ebola virus disease
ICU	intensive care unit
LB	lyme borreliosis
LCI	Coordination Outbreak Control, Netherlands
OIE	World Organisation for Animal Health
PPE	personal protective equipment
RIVM	National Institute for Public Health and the Environment, Netherlands
SOP	standard operating procedures
TBE	tick-borne encephalitis
TBEV	tick-borne encephalitis virus
TESSy	The European Surveillance System

Executive summary

Background

Within the broad 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 for the project is that affected communities are increasingly recognised as key resources that can be used during public health emergencies, and that the concerns and experience of ordinary people should be harnessed as an important part of the response.

The aim of this qualitative comparative case study project is to identify good practices related to community preparedness for tick-borne diseases. Two EU countries, Spain and the Netherlands, were selected for inclusion. Work in Spain focused around two cases of autochthonous infection with Crimean-Congo haemorrhagic fever (CCHF) virus that emerged in the Autonomous Community of Castilla y León in August 2016. Work in the Netherlands focussed on the first two endemic cases of tick-borne encephalitis (TBE) in the country, appearing in July 2016 in the Utrecht and Twente regions. The response to the TBE cases was undertaken within the wider context of prevention work on lyme borreliosis (LB) in the country.

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;
- Identify inter-sectoral collaboration between health and non-health-related sectors with regard to tick-borne diseases;
- Identify practices that could be of use for other EU countries in the area of public health preparedness.

Methods

A comparative case study approach was taken for this project which, in both Spain and the Netherlands, was based on three qualitative sources of evidence: documents; interviews with a range of technical experts working at national and Autonomous Community/provincial level, and focus group discussions with community representatives. Field work was conducted during a visit to Spain by the research team during the week of 13–17 November 2017; and in the Netherlands from November 17 to December 5, 2017. A total of 28 and 31 individuals took part in the interviews and in the focus group discussions in Spain and the Netherlands respectively. The data were subjected to thematic analysis, for which the themes were based on a theoretical preparedness cycle that includes the pre-incident, incident, and post-incident phases.

Findings

The major collective findings from Spain and the Netherlands are presented below in summary form for each of the public health preparedness cycle phases. All the points presented apply to both participating countries.

Pre-incident

Collaboration between zoonotic researchers and community-based partners (e.g. hunters) plays an important ongoing role in tick, deer and virological surveillance.

Regular intelligence-sharing coordination meetings involving both the human and animal health sectors are organised as part of the epidemic intelligence services by the national public health authorities.

While connections between the different sectors have in many cases been established at an official level, the zoonosis preparedness and response synergies between the authorities and the community are limited to groups who have close connections with animals, such as hunters, herders and farmers.

Protocols for tick-borne diseases as published by the national and regional public health authorities provide prevention information for specific risk groups and clinical guidelines for treatment, but they do not provide suggestions on the organization of community engagement for preparedness and response.

Incident phase

- The CCHF and TBE incidents in the participating countries were quickly resolved, as a result of which the response was led almost entirely by the public health authorities, with little active engagement from the potentially affected communities.
- No specific actions were considered necessary to reach out to specific groups during the incident phase, as the increased risk of infection through tick bites was not recognised at the time.
- Experience from other somewhat similar diseases (i.e. Ebola in Spain, and Q-fever and lyme borreliosis in the Netherlands) played an important role in framing aspects of the response.
- Critical information was not always expediently transferred through the correct channels to certain stakeholders responsible for public health.
- According to reports, the information disseminated to the public by national authorities about the emerging tick-borne diseases was widely trusted and believed.
- Media coverage was generally accurate and correct, but interest was limited and not sustained for more than a few days. Provincial, municipal and national level press offices were well able to cope with the demands of these incidents.
- Social media were monitored during both incidents, but no significant rumours or misinformation were identified.

Post-incident phase

- No substantive evaluation or overall 'after-action review' has been conducted to date for either incident, but some changes were made to specific protocols based on the respective experiences.

Good practices identified

As a result of this study, a set of good practices emerged for promoting collaboration and synergies between the authorities and the community. These include measures that have already been implemented in Spain and/or the Netherlands to a greater or lesser extent, as well as areas where improvements could reportedly still be made. They are presented as activities that may be adopted for use by other EU Member States.

a) Promoting collaboration and synergies between the authorities and the community

- Use pre-existing networks within the community, and particularly community actors that link different groups ('brokers'), in order to spread information about who may be at risk of tick-borne or other zoonotic diseases.
- Use pre-existing networks of disease-specific community actors for engagement with other, closely-related diseases.
- Cultivate relationships between zoonosis researchers and community-based monitoring networks such as hunters and foresters, for example by promoting citizen science initiatives that improve surveillance.
- Provide feedback on coordination and response activities to community members who contribute relevant data or information for surveillance and other preparedness activities.
- Conduct a stakeholder analysis of all community-based actors who may be involved in or affected by a tick-borne or other zoonotic outbreak or event.
- Adopt different approaches as appropriate when following up on the various categories of potentially exposed contacts within the community.
- View the community – including interest group associations that serve people who may be at risk of zoonotic infections – as a resource for optimising preparedness planning and response actions.
- Integrate protocols for effective community engagement into disease outbreak guidelines.
- Understand that building trust with the community is an essential component of any successful preparedness programme, but it takes time, commitment, and the building of personal relationships over the long term.
- Engage with the private sector as an opportunity to promote public preparedness.

b) Promoting inter-sectoral collaboration and synergies between the authorities

- Develop a 'One-Health', multi-sectoral approach which offers the possibility, by building trust as well as an understanding of the linkages between the various institutional stakeholders, to respond quickly to a zoonotic outbreak or event, identifying at-risk geographical areas, and then providing enhanced messaging on prevention and control for at-risk populations living there.
- Develop a protocol in advance of any zoonotic public health incident that includes provisional agreements with all relevant sectors for establishing a 'One Health Crisis Committee' built on mutual trust.

- Conduct multi-sectoral simulation exercises.
- Conduct a comprehensive stakeholder analysis and/or workflow analysis of all relevant authorities and agencies, including all relevant sectors.
- Recognise that different sectors have different interests that need to be taken into account in any inter-sectoral and collaborative response to a zoonotic outbreak or event.

c) Communication flows between the authorities and with the media and the community

- Ensure efficient and smooth information exchange at each different phase of an outbreak or event, both within and between all relevant stakeholder institutions, and between all relevant sectors.
- Prepare contingency plans for the press offices of provincial and municipal health authorities which may need support in responding to high volumes of press interest in the event of a serious outbreak.
- Build trusting relationships with journalists during peacetime: Good relationships between the authorities and journalists can benefit both sides.
- Communicate transparently with the community about ongoing processes during each of the different phases of an outbreak or event.
- Provide authoritative health information to the community through a spokesperson who is trusted both by the different sectors involved, and by the community.
- Identify and engage with hard-to-reach but potentially at-risk groups.
- Ensure that systematic efforts are made to monitor community perceptions of any public heath incident, for example through social media.
- Support community-based disease networks that can facilitate the coordination and implementation of public education and preparedness campaigns.
- Recognise any rural-urban divide in perceptions that may exist with regard to tick-borne diseases when designing risk communication strategies.

1. Introduction

EU Decision 1082/2013 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 [2]. 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[i], 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 focused around two autochthonous cases of infection with Crimean-Congo Haemorrhagic Fever (CCHF) virus that emerged in the Autonomous Community of Castilla y León in August 2016. In the Netherlands the focus was on Tick-Borne Encephalitis (TBE), with the first two endemic cases in the country appearing in July 2016. These TBE cases were considered within the broader context of a widespread and increasing incidence of lyme borreliosis (LB) in the Netherlands, and the associated networks that have evolved as a result.

[i] Previous ECDC case studies on institutional preparedness focussed on Ebola [29], MERS [30] and polio [31].

2. Aims and objectives

The overall objective of this work was to identify elements that should be considered for interoperability and resilience in public health emergency planning, and to support the implementation of EU Decision 1082/2013 on serious cross-border health threats.

The aim of this particular case study project, in both Spain and the Netherlands, was to collect evidence and identify good practices related to community preparedness for public health emergencies, with a view to summarising this information for use in other EU countries to improve public health preparedness at EU level. Tick-borne diseases formed the basis for the study, which aimed to:

- identify what has worked successfully, 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, identify and analyse inter-sectoral collaboration with respect to community-institutional synergies, and provide examples of collaborative efforts between health and non-health-related sectors;
- identify lessons learned and practices that could be of use for other EU Member States in the area of public health preparedness.

3. Methods and definitions

3.1 Study design and participants

A comparative case study approach was taken for this project, based on a variety of qualitative evidence sources. In both Spain and the Netherlands, these included documents; semi-structured qualitative interviews with a range of experts working at national and Autonomous Community/regional level, from both the health and non-health sectors and focus group discussions with representatives of affected communities. Interviews were conducted with the experts in order to allow for in-depth discussion of their professional perspectives and experiences, while the focus group discussions were conducted with the aim of developing insights into community norms and values relating to the topic.

Field work was conducted during a visit to Spain by the research team during the week of 13–17 November 2017; and in the Netherlands from 17 November to 5 December 2017.

The interview and focus group discussion participant categories were discussed and agreed in close collaboration with ECDC, the Spanish counterparts (based at the Coordination Centre for Health Alerts and Emergencies - CCAES) and the Dutch counterparts (based at the National Institute for Public Health and the Environment - RIVM). These are presented in Table 1 below.

Table 1. Interviewee and focus group discussion participant categories in Spain and the Netherlands

	Spain	Netherlands
National level interviews	• Ministry of Agriculture, Fish, Food and Environment • General Directorate of Public Health • Press cabinet/journalist	• Ministry of Health • RIVM Centre for Infectious Disease Control • State epidemiologists • Entomologist • Laboratories & diagnostics (RIVM)
Autonomous Community/ regional level interviews	• Public health authority • Environmental and Animal Health • Press cabinet or communication to the Citizen's Office • Human public health • Animal public health • Communication to the Citizen's Office	• Municipal health services (GGD) • Forestry service • Amsterdam Academic Medical Center • Agrarian personnel health service (STIGAS) • Wageningen University and Research Central Veterinary Institute
Focus group discussion with affected communities (Note: One or more people may have represented each category listed)	• Occupational Hazards Unit • Emergency room clinician • Local human public health services • Central human public health services • Human public health emergency team • Veterinary health emergency team • Hiker • Hunter • Veterinarian (focused on hunter activity) • Veterinarian (focused on livestock) • Farmers • Livestock farmer • Park/nature reserve worker	• General practitioner • Lyme patient organisation representatives • Scouting • School representative • Private property owner • Children's farm • Campground manager • Municipality employee • Community green maintenance worker • Local forester • City gardener • Hunter • Herder

Table 2. Number of interviews and focus group discussions, and respective number of participants; at national, Autonomous Community/regional and community levels, for Spain and the Netherlands

Spain	Health sector interviews (number of participants)	Non-health Sector interviews (number of participants)	Community focus group discussions (number of participants)	Total number of participants
National level	1 (2)	2 (4)	-	**6**
Madrid Autonomous Community	1 (1)	2 (2)	1 (6)	**9**
Castilla y León AC	1 (2)	2 (2)	2 (9)	**13**
Total number of participants	**5**	**8**	**15**	**28**

Netherlands	Health sector interviews (number of participants)	Non-health sector interviews (number of participants)	Community focus group discussions (number of participants)	Total number of participants
National level	6 (10)	0 (0)	-	**10**
Regional level	3 (4)	2 (2)	-	**6**
Community level	3 (3)	2 (2)	2 (10)	**15**
Total number of participants	**17**	**4**	**10**	**31**

3.2 Data collection

Documents

In Spain, background materials on CCHF were identified from online searches. Prior to the country visit, the Spanish counterparts from CCAES sent a set of press cuttings collected during the 2016 CCHF event, clips of relevant TV news stories and links to the official websites concerned with tick-borne diseases. In the Netherlands, the National Institute for Public Health and the Environment (RIVM) provided a review of relevant resources prior to the country visit, which were downloaded for analysis. In addition, media clippings, peer-reviewed journal materials and background study reports on both TBE and LB were identified through database searches. Additional documentary materials were collected from the interviewees and focus group discussion participants during both country visits.

Interviews and focus group discussions

An initial set of questions for the qualitative, semi-structured interviews and for the focus group discussions was derived from a literature review that had been conducted for ECDC during an earlier phase of this community engagement project [2]. The questions were arranged according to the preparedness cycle phases – pre-incident, incident and post-incident [3, 4] – and then adapted according to comments received from the Spanish and Dutch counterparts. Within 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 identifying lessons learned. In order to facilitate the interview and the focus group discussion process, the questions were translated into Spanish and Dutch as appropriate, and sent to the participants in advance to enable them to prepare.

The questions were designed to be broadly relevant to all interviewee categories, but the focus of the questioning varied according to the position and particular expertise and experience of each individual interviewee or focus group. All interviews and focus group discussions were conducted face-to-face, except for three interviews in the Netherlands which were held via Skype or on the phone for logistical reasons.

3.3 Ethical considerations

Written informed consent was obtained from all interviewees and focus group participants.

3.4 Data analysis

The notes from the interviews, focus group discussions and participant observation were subjected to thematic analysis, using 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. The analysis was conducted within the framework of the theoretical preparedness cycle mentioned above [3, 4]. The analysis also distinguished between the national and provincial/Autonomous Community levels.

3.5 Definitions

A few key terms have been used in the course of this case study project that require definition.

- '*Community*' refers here to populations that have been directly affected by or may have been at risk from the disease in question. The 'community' is seen as distinct from the government authorities who are tasked with addressing the disease. Note that in order to avoid confusion between affected communities and the Spanish administrative term 'Autonomous Community', reference is made throughout the text to Castilla y León 'Autonomous Community' and Madrid 'Autonomous Community'.
- '*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*' [5].
- '*Synergy*' refers in this report to the added value that derives from the process and outcome of two or more stakeholders or sets of stakeholders working together towards a common goal. The stakeholders could be either from the community, or they could be 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 more than either could have achieved alone, and these benefits are, most probably, 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*' [6].
- '*Green partners*' in this report refer to outdoor-oriented stakeholders, such as estate managers, owners of conservation management organisations, hunters, forest or land owners, natural camping grounds, and smallholding farmers.

4. Findings

The main collective findings from Spain and the Netherlands are presented below, framed within the public health preparedness cycle described above.

4.1 Pre-incident phase

Collaboration between zoonotic researchers and community-based partners, such as hunters plays an important ongoing role in tick, deer and virological surveillance.

Spain: Tick surveillance has been ongoing in Spain for 25 years, including intermittently for CCHF since 2009: an infrastructure was thus already in place before the 2016 event. The surveillance system works in two directions: firstly, via the Ministry of Agriculture to the Autonomous Community veterinarians and hunters in the field who are responsible for collecting and sending in tick samples; and secondly, from those involved in analysis of the samples and the epidemiologists, who send their findings to hospitals and decision-makers in the Autonomous Communities and the Ministry of Health, who subsequently send them on to international organisations such as the World Organisation for Animal Health (OIE) and the European Food Safety Authority.

Netherlands: Zoonotic researchers working for RIVM, the Dutch authority responsible for response, work in close collaboration with a host of 'green' partners (e.g. land owners, estate managers, hunters, herders). A collaborative synergy existed in which the RIVM supported these community-based actors with laboratory analysis in return for information and data sampling (e.g. monthly tick sampling by nature education volunteers in at least 12 locations throughout the Netherlands from 2006 to 2016). RIVM facilitated this situation by spending 20% of the tick-borne disease research budget on stakeholder analyses and engagement. In addition, an internet-based participatory science project called the Tick-Radar, set up in the context of LB, facilitated clinical detection of the first case of TBE because the infected individual was an active participant in Tick-Radar, and he understood the importance of keeping and sending in the infected tick for an LB diagnosis.

Collaboration between human and animal health sectors

Regular intelligence-sharing and coordination meetings involving both the human and animal health sectors are organised as part of the epidemic intelligence services by the national public health authorities.

Spain: Collaboration between the Ministry of Health and the Ministry of Agriculture is well established, with monthly meetings on issues related to human and animal health, and ad hoc meetings as necessary. The tick surveillance mechanism is integrated into this collaboration, along with other relevant stakeholders, through a formalised and well developed system.

Netherlands: After the 2011 Q-fever outbreak, a national zoonotic signalling and response structure was established. Meetings are held on a monthly basis to conduct integrated human and veterinary risk analysis including the Animal Health Laboratory Service, RIVM Coordination Outbreak Control (LCI), the Dutch Food Safety Administration, the Central Veterinary Institute, and the Faculty Veterinary Sciences at the University of Utrecht. The structure further facilitates inclusion of inter-sectoral expert advice and consultation with patient groups and animal sectors.

Connections between sectors

Connections between different sectors have been established at an official level, however the zoonosis preparedness and response synergies between the authorities and the community are limited to groups who have close connections with animals, such as hunters, herders and farmers.

Spain: The primary stakeholders who were prepared for a zoonotic public health event – even if they were not specifically prepared for CCHF – included the Ministry of Health, Social Services and Equity, the Ministry of Agriculture, the public health authorities in the two affected Autonomous Communities, and the Autonomous Community veterinarians (who provided the main substantive link to the community at risk of tick bites). Links between these four sets of stakeholders were well established and they were built on clearly defined protocols, which were also applied for health workers at risk of potential nosocomial infection. Pre-existing connections and synergies between the authorities and the community at risk of tick bites were limited to contacts with hunters and farmers through veterinarians.

Netherlands: Dialogue between the Ministry of Health, Sport and Welfare and Ministry of Agriculture, Nature and Food Quality and the Ministry of Economic Affairs and Climate Policy is ongoing, but coordination between the sectors is challenged by different priorities (e.g. forests as tourist and leisure opportunities rather than areas with tick-borne risks) and administrative geography (e.g. the lack of congruence between agricultural policy at province level and health policy through different health and safety regions). Community-based partners integrated into preparedness and response systems primarily include veterinarians and wildlife professionals whose work is directly

related to surveillance and detection. With the exception of occupational health professionals, green partners (e.g. hunters, foresters, conservation organisations) are less integrated as a resource, and are seen more as partners who can disseminate information to community members. Other community-based actors such as scouts, schools, and children's farms remain outside the general response infrastructure. However, patient groups have negotiated themselves a leading role in the newly established Dutch Lyme Expertise Centre with relevance for TBE.

Availability of protocols

Protocols for tick-borne diseases, as published by the national and regional public health authorities, provide prevention information for specific risk groups and clinical guidelines for treatment, but they do not provide suggestions on how to organise community engagement for preparedness and response.

Spain: The website for CCAES (Coordination Centre for Health Alerts and Emergencies) at the Ministry of Health, Social Services and Equity includes:

- General information and recommendations for citizens: transmission, symptoms, diagnosis and treatment for CCHF; treatment-seeking behaviour; prevention and control measures undertaken by the Ministry of Health, Social Services and Equality; surveillance; coordination activities between the human and animal health and the environmental sectors; tick removal; control of ticks with repellents and insecticides.
- Technical information for health professionals: disease epidemiology; the risk of CCHF transmission in Spain; surveillance; the vector; virulence and lethality; diagnosis; disease development; case notification; contact tracing; hospitalisation and isolation; safe collection and handling of biological samples; protection against infection among health workers, including PPE; and how to deal with a tick bite[ii].

Netherlands: For TBE, RIVM-LCI developed health guidelines in October 2010, which were amended on July 21 2016 because of the new human-TBE epidemiological situation, with additional resources included in an addendum on 15 August 2017. However, apart from a list of four risk groups (foresters, woodcutters, campers. And hikers), this guideline does not provide advice on community engagement or stakeholder analysis from a preparedness or response perspective[iii].

4.2 Incident phase

Engagement of affected communities in response actions

The CCHF and TBE incidents in the participating countries were resolved by response actions led almost entirely by the public health authorities, with relatively little engagement from potentially affected communities.

Spain: There were three major official actors engaged over the course of the CCHF event: The Ministry of Health at national level; the Madrid Autonomous Community, where both cases had been hospitalised and most of the follow-up and communications were therefore required; and Castilla y León Autonomous Community, where the index case had been infected. The response consisted solely of a triangle of communication and coordination activities among these three official actors.

With regard to the affected communities, concerns were raised by health workers in Castilla y León Autonomous Community, who asked their leadership what actions should be taken in the event of a patient presenting with suspected CCHF infection at an emergency room or in a primary healthcare setting. A protocol, adapted from a pre-existing set of standard operating procedures (SOPs) for viral haemorrhagic fevers, was produced on 2 September 2016 and circulated to the appropriate facilities. This was one of the very first official activities in the response to CCHF, and the speed with which it was arranged was at least partially due to pressure from the health workers themselves.

No specific actions were reportedly taken by interest groups or the community more broadly in relation to the prevention of tick bites.

Netherlands: The two TBE cases were identified and diagnosed in the Netherlands within just one month. Rapid signalling and response coordination included inter-sectoral expert consultation, but community engagement was limited to the dissemination of information. An explicitly medical human risk perspective was maintained, with no direct role in response for 'green' partners such as the forestry service. Engagement of community actors remained focussed on LB, to provide complementary prevention goals.

Reaching vulnerable groups

Infection through tick bites was not recognised as an elevated risk at the time and as a result no specific action was taken to reach out to particular groups during the incident phase.

[ii] For further details: http://www.msssi.es/profesionales/saludPublica/enfermedadesEmergentes/Crimea_Congo/home.htm
[iii] For further details see: https://lci.rivm.nl/richtlijnen/tekenencefalitis

Spain: After the diagnosis of CCHF on 31 August 2016, a press release was prepared for dissemination by the communications team in the Madrid Autonomous Community the very next day, 1 September 2016. Subsequently, a press conference was held to explain the situation regarding the two confirmed cases to the media. From that moment, information to the media was provided regularly by the communication team of the Madrid Autonomous Community.

In the Castilla y León Autonomous Community, a press release was developed in coordination with the animal and environmental health departments, with a message to the public to stay calm, accompanied by reassurances that the risk of infection was low. A link to information on their website was included, with details of how to protect against ticks and how to remove them.

Information was therefore disseminated to the general public but not to specific groups at risk of infection from tick bites.

Netherlands: After detection of TBE, the RIVM-LCI conducted a stakeholder analysis of risk groups, such as people working outdoors and those frequenting forests. In the stakeholder analysis, the coordination group also identified what information the stakeholders required from the RIVM-LCI and vice-versa. However, because there were only two cases of TBE, no extra efforts were made to reach out to risk groups. At regional level, vulnerable groups were identified, including asylum seekers who lived in forested areas, hikers, foreign tourists, pet owners, scout groups, schools, daycare facilities in green areas, garden owners, and specifically also volunteers working in green areas where the occupational health services were not particularly experienced with this issue.

Experience from other somewhat similar diseases (i.e. Ebola in Spain, and Q-fever and lyme borreliosis in the Netherlands) played an important role in framing aspects of the response.

Spain: The CCHF event demonstrated that lessons learned from Ebola were taken into consideration – a case of Ebola virus disease was detected in Madrid in 2014 in a healthcare worker who had cared for an infected Spanish missionary repatriated from West Africa [7] – and many institutional crisis response plans had been updated. These included protocols for safe treatment of patients with viral haemorrhagic fevers at national level, which could easily be adapted at Autonomous Community level. There was also consensus among the interviewees that lessons had been learned during the Ebola crisis on risk communication to the public, and this had positive implications for the handling of communications during the CCHF event.

Previous experience with Ebola probably had an impact on the CCHF event in two areas. At the political level, there could have been a degree of anxiety among certain political actors during the CCHF event that the public would perceive the situation to be getting out of control. Consequently, the flow of information during the critical first 48 hours of the event was managed centrally, which led to delays in the sending out essential information to people at the operational level. In addition, among individual health workers, there was a residual fear of viral haemorrhagic fevers because of the Ebola incident in 2014, and this caused some people to be reluctant to engage with patients who may have been exposed to CCHF.

Netherlands: A major Q-fever outbreak between 2007 and 2010 led to a need for inter-sectoral collaboration and the identification of major challenges regarding data-sharing, privacy and the balancing of commercial and agricultural risks against human health risks. This led to the establishment of a national zoonotic signalling and coordination structure. However, it also led to a conviction among some people working at RIVM-LCI that non-medical involvement in decision-making regarding medical risk assessment was not always optimal; and that if it was to be included, it should not begin until the implementation phase of any response.

In addition, because the generic processes for addressing TBE overlapped with those for LB, and because there had only been two autochthonous TBE cases, RIVM-LCI took the decision to align preparedness and response efforts within the established LB mechanisms. This meant that although signals about emerging TBE were sent out to a selected group of stakeholders, broader public communication focused on LB prevention.

Communication channels

Critical information was sent to some of the stakeholders responsible for public health but not always expediently transferred through the correct channels.

Spain: The CCHF alert came through the Ministry of Health to the General Director of Public Health in the Castilla y León Autonomous Community. Some, but not all key staff members were then informed. This meant that information about the cases reached many of the staff via unsubstantiated reports in the media, or directly from journalists who approached them asking for information that they could not provide.

A bottleneck was also reported regarding the communication channels between the Castilla y León Autonomous Community and the Madrid Autonomous Community, which led to the creation of parallel communication systems during the first 24–48 hours of the response. Delays resulted in important information not reaching responders in an appropriate timeframe. These delays appear to have been a direct consequence of the policy that key aspects of the information exchange process between Autonomous Communities are supposed to be authorised by General

Directors who have political oversight over the process, with some information also passing through the Ministry of Health. Some technical experts therefore found it necessary to communicate directly with their counterparts in the other affected Autonomous Community.

Netherlands: Stakeholders involved with the National Park in which TBEV antibodies were first identified in deer were notified of the presence of the virus, but they were asked to keep this information restricted until further notice. The stakeholders complied, but information about the subsequent detection of TBE in humans was not communicated to them directly, and instead they read about it in the media. This lack of reciprocity left managers unable to prepare their staff for the public and media attention. It also had an impact on relations between RIVM zoonotic researchers and community-based animal and nature groups (e.g. hunters, herders) which had been collaborating on signalling and surveillance activities.

Dissemination of information to the public

The information disseminated to the public by the national authorities about the emerging tick-borne diseases was thought to be widely trusted and believed.

Spain: By being predictable and transparent, and by relying on pre-existing relationships of trust with individual journalists, the press offices of the Ministry of Health and the Autonomous Communities sought to pre-empt any doubts in journalists' minds about what was happening, thereby avoiding sensationalist reporting that could create public alarm. The overall result of these efforts was accurate and factual coverage, and a near absence of misinformation (there was just one case of a media outlet incorrectly reporting that there had been another confirmed case when in fact the samples had not yet been processed). People at community level were aware of the media coverage on CCHF, but – as intended by the authorities – they were not particularly concerned.

Netherlands: Overall, information about TBE was not questioned by the public. A general consensus exists that the RIVM has a unique and increasingly important role to fulfil as a provider of neutral, evidence-based information for the public domain. In addition, educating the public about the process of ongoing investigations was seen as helpful to increase public trust in the leading role of the institute. However, RIVM was seen as unnecessarily cautious in its engagement with the public beyond standard information dissemination on LB diagnosis and treatment.

Media coverage

Media coverage was generally accurate and correct, but interest was limited and not sustained for more than a few days. Provincial, municipal and national-level press offices were well able to cope with the demands of these incidents.

Spain: After an initial spark of interest, media coverage of CCHF was quite limited. The two cases emerged towards the end of the summer holidays, and journalists were generally more interested in covering other issues during this period. Analysis of several national and regional newspapers identified 45 articles on the subject up until 22 September, 23 (51%) of which were published by 6 September, indicating a rapid loss of interest in the topic after the first week. Topics covered included the background of the disease, modes of transmission, preventive measures, symptoms, and the case fatality rate; and it was notable that coverage tended to reflect both the tone and content of the official updates. There was a strong emphasis on the importance of people being alert but not alarmed and several of the articles also explained what the Ministry of Health and the public health authorities in the Madrid Autonomous Community were doing to keep the virus from spreading further.

Netherlands: RIVM issued a press release to the media on the first TBE case, but not the second. Media attention towards TBE was accurate and remained limited in volume. Only a few media reports had previously been published on the fact that TBEV had been found in deer prior to the identification of the human cases. After the human cases were recognised, all the reports identified mentioned RIVM, and they were generally factual and short. Topics covered included the background of the disease, modes of transmission, and symptoms. News articles emphasised that ticks spread the virus to humans and that the risk of TBE infection was low.

The limited media and political attention was striking given the potential implication of a new, endemic infectious disease. However, this event occurred when the media were preoccupied with the emergence of Zika virus.

Monitoring of social media

Social media were monitored during both incidents, but no significant rumours or misinformation were identified.

Spain: The communications team at the Ministry of Health receives alerts from a range of official social media sources, but not from the community itself. The public health authorities at one of the Autonomous Communities reported that they do monitor social media by following specific institutions and specific hashtags – however if a keyword is missed, a search may not pick up a point of interest. No significant rumours were reported on social media regarding CCHF.

Netherlands: Active social media monitoring by RIVM-LCI reported no rumours. The monitoring system uses dedicated software packages and communications staff, who, if necessary, can find ways to privately contact active, well-connected social media users in order to engage with them in dialogue. No such intervention was needed in this case.

4.3 Post-incident phase

Post-event evaluations

Some changes were made to specific protocols based on the respective experiences, but no substantive evaluation or overall 'After Action Review' has been conducted to date for either incident.

Spain: No substantive evaluation or 'After Action Review' was conducted after the CCHF event. According to the respondents, this was due to limited resources (financial and human) and, according to some insiders, the prevailing organisational cultures in the Ministry of Health and the two affected Autonomous Communities. A special unit for evaluation had been established in one of the Autonomous Communities shortly before the financial crisis of 2008, but it was disbanded around five years ago, reportedly due to different priorities in health policies.

Despite the absence of an overall systematic evaluation, informal evaluations were nonetheless conducted on specific matters at both national and Autonomous Community level, and changes were made to particular SOPs and protocols accordingly. These included laboratory protocols; CCHF virus surveillance; and public information on tick removal.

Netherlands: No substantive evaluation, or 'After Action Review' was conducted after the TBE event. The emergence of TBE is still being researched and the case is considered ongoing, but no new cases of TBE have been identified in 18 months. In addition to published case reports, a small review was written by the Utrecht Municipal Health Service with inter-sectoral partners. At present, there are several ongoing epidemiological studies. In response to the event, RIVM-LCI has focused on increasing awareness among medical partners to facilitate signalling and detection of TBE, and it has also adapted public information on tick-bites to include more TBE-related information.

5. Good practices

While the previous section presented the main findings from the CCHF event in Spain and the TBE event in the Netherlands, this section outlines a set of suggested good practices for promoting collaboration and synergies between authorities and communities. These good practices could also be adopted in other EU Member States as part of preparedness and response activities for zoonotic and other infectious disease outbreaks and events. They include points that have already been implemented in Spain and/or the Netherlands to a greater or lesser extent, as well as areas where improvements could still be made.

5.1 Promoting collaboration and synergies between the authorities and the community

- Use pre-existing networks within the community, and particularly community actors that link different groups ('brokers'), in order to spread information about who may be at risk of tick-borne or other zoonotic diseases. Hunters in Spain have close contact with one another and with the authorities (licensing, finding and reporting sick animals); while livestock farmers are regularly in touch with veterinarians. In the Netherlands, the Green Lyme Working Group connects various stakeholder groups who may otherwise not receive health information. Such channels can be used to disseminate prevention information to people who are potentially at risk of infection.
- Use pre-existing networks of disease-specific community actors for other, closely-related diseases. The extensive community-based network of LB in the Netherlands is an effective platform to channel information and obtain additional resources for TBE preparedness and response. It is important that such disease-specific community actors are informed of the different risk profiles of these closely-related diseases, particularly with regard to any differences in transmission risk and disease virulence.
- Cultivate relationships between zoonosis researchers and community-based monitoring networks such as hunters and foresters, for example by promoting citizen science initiatives that improve surveillance. Such relationships have proven critically important in the tick surveillance systems of both Spain and the Netherlands.
- Provide feedback on coordination and response activities to community members who contribute relevant data or information for surveillance and other preparedness activities. People will generally be more cooperative with authorities in surveillance and other preparedness activities (such as hunters sending in ticks for analysis, or identifying sick animals) if they receive regular updates on the usage of the datasets to which they are contributing. For example, by sending them annual summaries showing the geographical patterns of tick infestation.
- Conduct a stakeholder analysis of all community-based actors who may be involved in or affected by a tick-borne or other zoonotic outbreak or event. Such an analysis should include details on who conducts which activities, with whom, and how, as well as which stakeholders act as brokers between the various components of the network.
- Adopt different approaches as appropriate when following up different categories of potentially exposed contacts in the community. Health workers who may be exposed to an infectious zoonotic agent can be followed up through professional channels, but people exposed through direct contact with ticks or other vectors will need to be identified using alternative means. Contact follow-up protocols need to be sufficiently flexible to take these different exposure categories into account.
- View the community – including interest group associations that serve people who may be at risk of zoonotic infections – as a resource for optimising preparedness planning and response actions. An informed, at-risk community understands the challenges to adopting effective preventive practices. Through dialogue with well-placed community representatives, it may be possible to identify areas where improvements can be made in preparedness, surveillance and response that can then be disseminated either to the wider population or to specific risk groups, as appropriate.
- Integrate protocols for effective community engagement into disease outbreak guidelines. Guidance may be needed on how to undertake community engagement activities, specifically in the case of zoonotic diseases.
- Building trust with the community is an essential component of any successful preparedness programme, but it takes time, commitment, and the building of personal relationships over the long term. The development of trust between health authorities and LB patient organisations in the Netherlands was the result of long-term discussions and patience. An important factor in the Dutch context was the recognition of shared objectives, and working on the basis of trusting and sincere personal relationships.
- Engage with the private sector as an opportunity to promote public preparedness. An open, yet critical engagement with commercial enterprises can help to make use of these networks positively for public benefit. For example, in the Netherlands, the Provincial government of Flevoland has promoted a business development strategy to capitalise on private initiatives, such as companies developing and providing insect sprays.

5.2 Promoting inter-sectoral collaborations and synergies between the authorities

- Develop a 'One-Health', multi-sectoral approach which offers the possibility, by building trust and an understanding of the linkages between the various institutional stakeholders, to respond quickly to a zoonotic outbreak or event, identify geographical areas at risk and provide enhanced messaging on prevention and control for at-risk populations living there. Tick surveillance is one example of where multi-sectoral coordination can provide invaluable information for the public health authorities, through a 'One-Health' approach including the Ministry of Health and the Ministry of Agriculture.
- Develop a protocol in advance of any zoonotic public health incident that includes provisional agreements with all relevant sectors for establishing a One-Health Crisis Committee, built on mutual trust. By ensuring that such a multi-sectoral protocol is already in place, decisions can be made quickly and efficiently during the critical first 24–48 hours of a zoonotic disease incident or outbreak.
- Conduct multi-sectoral simulation exercises. Multi-sectoral simulation exercises, including both national and regional level authorities as well as relevant ministries (e.g. Agriculture and the Environment), have the potential to identify bottlenecks and gaps in preparedness and response protocols that can then be addressed. Such exercises could include autochthonous cases of zoonotic disease.
- Conduct a comprehensive stakeholder analysis and/or a workflow analysis of all relevant authorities and agencies, including all relevant sectors. A stakeholder analysis could include identification of key brokers, such as people working in occupational health services in the green sector, who could be called upon to reach out to other groups and individuals in the event of an outbreak.
- Recognise that different sectors have different interests that need to be taken into account in any inter-sectoral and collaborative response to a zoonotic outbreak or event: The primary concern of the Ministry of Agriculture is the financial welfare of farmers, the Ministry of Economic Affairs aims to promote opportunities for recreation and tourism, while the primary concern of the Ministry of Health is, naturally, human health. These interests may come into conflict if, for example, mass culling of livestock or poultry, or the closing of a national park is necessary in order to protect the public from a zoonotic disease.

5.3 Communication flows between the authorities and with the media and the community

- Ensure efficient and smooth information exchange at each phase of an outbreak or event, both within and between all relevant stakeholder institutions, and between all relevant sectors. It should always be a priority to ensure that operational personnel and technical experts receive all the relevant information as soon as it is obtained and validated.
- Prepare contingency plans for the press offices of provincial and municipal health authorities who may need support in responding to high volumes of press interest in the event of a serious outbreak: Since neither the CCHF nor the TBE incidents developed into major outbreaks, the provincial and municipal press offices were able to manage local level media requests for information. However, if the incidents had turned into significant events with sustained and intensive media interest, it would have been important to have additional support from colleagues, for example at national level.
- Build trusting relationships with journalists during peacetime – good relationships between the authorities and journalists can benefit both sides. Journalists can be important sources of information for what is going on in the community, while also disseminating key information to at-risk populations. Working with individual journalists who are known to be reliable during a public health incident can offer significant mutual benefits.
- Communicate clearly with the community about ongoing processes during each of the different phases of an outbreak or event: For example, updates on research investigations, even if results are not yet conclusive.
- Provide authoritative health information to the community through a spokesperson who is trusted both by the different sectors involved, and by the community: Consistent and regular use of a trusted, media-trained spokesperson, who may become the 'public face' of the official response, is an essential component of efforts to manage the community response to a zoonotic disease incident or outbreak.
- Identify and engage with hard-to-reach but potentially at-risk groups. In relation to tick-borne diseases, such groups may include hikers, local and/or foreign tourists, pet owners, scouts, schools, day care facilities, garden owners, and volunteers working in nature reserves and other similar areas. Risk communication campaigns may need to be tailored to the specific needs of each group, and in some cases, language translation could also be necessary.

- Ensure that systematic efforts are made to monitor community perceptions of any public heath incident, including through social media. By monitoring community perceptions of an issue, it will be possible for the authorities to respond to any misinformation or rumours that may emerge. This process can also help to identify new cases or clusters, to which the authorities can then respond. Social media have been used in some settings to monitor community perceptions, as has documenting the topics of concern raised on telephone hotlines.
- Support community-based disease networks that can facilitate the coordination and implementation of public education and preparedness campaigns: The annual 'Week of the Tick' campaign in the Netherlands is organised by a group of cross-sectoral stakeholders, and has proven to be an effective means of reaching out to stakeholders who may otherwise have been missed by the authorities.
- Recognise any rural-urban divide in perceptions that may exist about tick-borne diseases when designing risk communication strategies. In the Spanish case study, there was a perceived divide in concern between the urban and rural populations, whereby ticks were seen as a greater problem by those living in the city, who are at lower risk, than by those in rural areas who are affected by them on a more regular basis. This has implications for any risk communication strategy. Wherever such divided perceptions are found, rural and urban populations should be targeted with different messages, and possibly disseminated via different channels.

6. Study strengths and limitations

6.1 Strengths and limitations

This study benefitted from the wide range of professional backgrounds represented by the interviewees and focus group participants in both Spain and the Netherlands, and from the inclusion of stakeholders at each of the national, Autonomous Community/provincial, and community levels. Furthermore, all the categories of respondent who were identified as being of significant importance to the topic were included in the research.

The semi-structured qualitative interview and focus group discussion methodology adopted in this study encouraged people to speak about issues in the way that they wanted, and to raise topics that *they* felt were important. Although it was a relatively small project that included the voices of just 28 and 31 people in Spain and the Netherlands respectively, it is likely that most, if not all of the core points relating to preparedness for and response to the 2016 CCHF and TBE events in these two countries were identified.

In Spain, the research team was accompanied to all the interviews and focus group discussions by officials from CCAES. In the Netherlands, an independent biological consultant contracted by RIVM participated. It is possible that the presence of these staff could have biased the responses of some interviewees or focus group participants, as they may not have wanted to share certain issues with national officials, or outside consultants. If this was the case, it is unlikely that it caused significant bias in the database, as most issues were discussed with more than one respondent. Moreover, while there was not universal agreement on everything, the study participants generally complemented each other's content rather than contradicting it. The presence of national authorities during discussions with autonomous and local communities possibly helped to strengthen relationships and understanding at the national and sub-national level.

6.2 Further steps

Consideration could be given to focussing future operational research on how best to implement, evaluate, and sustain the good practices identified above, and to develop more effective cooperation between communities and authorities in preparedness and response to zoonotic diseases.

Such work would complement global efforts to implement international conventions, such as the 2015 Sendai Framework for Disaster Risk Reduction and the 2005 Bangkok Charter for Health Promotion in a Globalized World, while also building on the principles outlined in the 2005 International Health Regulations and EU Decision 1082 to strengthen community engagement in public health emergency preparedness.

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Annex 1. Study context

Spain and Crimean-Congo haemorrhagic fever

Spanish health systems

Decentralisation of the Spanish health system began in 1986 and was finalised in 2002 when core health competences were transferred to the regional, or Autonomous Community level. There are 17 Autonomous Communities in the country and two autonomous cities, each of which is responsible for the organisation and provision of health services. Consequently, the Ministry of Health, Social Services and Equity has a strategic and policy making role but relatively limited operational power. Its roles include coordinating health policy, health planning and guidelines, international and border-related health issues, legislation on pharmaceutical products, surveillance, and health information systems. Minimum standards are set at national level which all Autonomous Communities must meet, but which they may also exceed if they choose to prioritise certain areas.

In the event of a public health emergency, each Autonomous Community is required to have an Autonomous Focal Point available to coordinate with the National Focal Point. The National Focal Point works out of the Coordination Centre for Health Alerts and Emergencies (CCAES), which is placed within the Directorate General of Public Health, Quality and Innovation in the Ministry of Health. Thus, a network of focal points has been established to facilitate continuous and rapid communication during any public health event or emergency that may have implications at either national or international level.

Crimean-Congo haemorrhagic fever

CCHF is endemic in Africa, the Balkans, the Middle East, and western and south-central Asia. Turkey is one of the most affected countries in the world: between 2002, when the first cases were detected there, and 2016, more than 9 700 patients were reported, with an overall case fatality rate of just under 5% [8]. This rate is lower than that found in many other parts of the world, which is probably due in part to the good surveillance system that has been established there. This, along with high levels of awareness both in the community and among health workers, facilitates the early detection of individual CCFH cases which can significantly reduce fatality rates [9].

In 2014, 25 EU/EEA countries provided information on CCHF through the European Surveillance System (TESSy). Eight cases were reported from Bulgaria and one from the United Kingdom (the latter imported from Bulgaria) [9, 10]. No other EU/EEA countries reported cases that year [11]. In 2015, four cases were reported to TESSy, all of them from Bulgaria [12].

The increasing incidence of the disease worldwide is probably the result of climate and environmental change: changes in temperature and precipitation affect tick density and activity levels. There is no specific case definition for CCHF in the EU, but the generic case definition for viral haemorrhagic fevers is used. There is also no vaccine for CCHF, but Ribavirin is used as an antiviral treatment, even though there remains an ongoing debate about its efficacy for the disease. Commercial assays for CCHF nucleic acid detection exist, but confirmation by additional assay is highly recommended [13] [14].

Since CCHF is one of very few tick-borne diseases that can be transmitted from human to human, particular efforts are required to control its spread in healthcare settings, especially from infected patients to the health workers caring for them. A study conducted in medical units in twenty-three Eurasian countries found that there was a high risk of hospital-acquired CCHF in many of these settings. However, the existence of suitable isolation units in all the facilities surveyed along with the availability of personal protective equipment (PPE) in most units reduced this risk. Most facilities also provided training for at-risk staff, but additional education was reportedly needed on disinfection of medical environment, waste management and PPE use [15].

Other risk groups for CCHF include people who are exposed to ticks through their occupation or lifestyle, such as livestock farmers, shepherds, veterinarians, slaughterhouse workers, hunters, and hikers. Travellers to endemic countries are not generally considered to be at high risk, with an estimation of around one case of CCHF infection in one million journeys to endemic areas [16].

In 2010, CCHF virus (CCHFV) was identified in ticks in Spain during a study at a game reserve in Extremadura Autonomous Community, a region of the country bordering Portugal. Ticks from other parts of Spain (Castilla León, Castilla la Mancha, Aragón and La Rioja) were found to be negative for the virus in the same study. Subsequently, research conducted in 2011 in Madrid Autonomous Community found that 50% of all the ticks captured were *Hyalomma lusitanicum* (which, together with *Hyaloma marginatum*, is a vector for CCHFV), but CCHF itself was not investigated in this study. Another study, conducted in Castilla y León Autonomous Community in 2014, looked for CCHFV in ticks obtained from slaughterhouses, but failed to find any. Further studies between 2011 and 2013 in the same areas identified infected *H. Lusitanicum* ticks only in the above-mentioned game reserve in Extremadura. Thus, at the time of the 2016 CCHF event in Spain, there was no knowledge of any possible risk to any populations in the country outside Extremadura, and even there, the risk was limited to a small area. There is, however, consensus that future sporadic human cases may occur in Spain [11].

The two CCHF cases: key events and timeline

The index case was a 62-year old man who had been hiking on 14 August 2016 in Ávila province, Castilla y León Autonomous Community, which is where he most likely became infected through contact with a tick. He suffered an onset of symptoms on 16 August and was admitted to hospital on 18 August, before being transferred to the Intensive Care Unit (ICU) of the Infanta Leónor Hospital in Madrid on 19 August. He was then transferred again to an isolation room at the ICU of the Gregorio Marañón Hospital in Madrid on 23 August, where he died on 25 August with a diagnosis of liver failure brought on by hepatitis. There was no suspicion of CCHF, and consequently there were no efforts to protect any of the family members, health workers, and laboratory technicians with whom he or his biological samples had had contact prior to his death. Similarly, the undertakers who prepared his body for burial were unaware of his infection, so they took no special precautions to protect themselves.

The second CCHF case was a 50-year-old health worker who had taken care of the patient while in the ICU between 19 and 23 August. She developed symptoms herself on 27 August and went to the emergency room, but was sent home. She returned, having failed to recover, and was then hospitalised before being sent to an isolation unit. However, the doctors were unable to provide her with a diagnosis. When she recognised that some of her own symptoms were similar to those exhibited by the index case and mentioned this to her doctors, the connection between the two individuals was made. The family of the index case was then approached and asked what environmental contacts he might have had. Tests were conducted, and the diagnosis of CCHF for both patients was confirmed on August 31.

The Netherlands and tick-borne encephalitis

Dutch healthcare and outbreak response system

According to the Dutch Public Health Act, infectious disease control is the responsibility of the 422 municipalities (*Gemeenten*). Serving these municipalities are 24 municipal health service regions (*Gemeentelijke Gezondheidsdienst*, or GGD), which coincide with disaster/crisis medical safety regions responsible for disaster medicine and pandemic preparedness, or the Medical Emergency Management Region (*Geneeskundige Hulpverleningsorganisatie in de Regio* - GHOR).

In the event of a national public health emergency, the National Institute for Public Health and the Environment (RIVM) Centre for Infectious Disease Control (CIb) coordinates the response. RIVM is an independent institute which advises on health and environment, with its work primarily commissioned by Dutch ministries and inspectorates. RIVM also undertakes projects within international frameworks. The centre coordinates the control of infectious diseases and is responsible for rapid and efficient communication about outbreaks nationally and regionally throughout the Netherlands. In the event of an outbreak, the RIVM is responsible for providing scientific advice on outbreak control measures to the government and arranging implementation by health professionals.

In recent years, the Netherlands has been affected by zoonotic outbreaks such as avian influenza in 2003 and Q-fever from 2007–2010, as well as tularemia. In response to these events, two Dutch Ministries – the Ministry of Health, Wellbeing, Sport and the Ministry of Economic Affairs – developed a collaborative protocol and zoonotic risk-analysis and response structure in 2011 [17]. Through this structure, inter-sectoral advice is solicited by zoonotic experts and standard zoonotic stakeholder lists created for coordination and response teams. In the case of a complex infectious disease outbreak, a special Outbreak Management Team Zoonosis advises the ministries on risk, management options and communication, including consultations with representatives from patient organisations and animal sectors.

Tick-borne encephalitis

Tick-borne encephalitis, or TBE, is a human viral infectious disease involving the central nervous system. According to the US CDC [18], symptoms are non-specific in approximately two-thirds of patients infected with the European TBE virus, including fever, malaise, anorexia, muscle aches, headache, nausea, and/or vomiting. However, a second phase of disease occurs in 20–30% of patients, involving the central nervous system with symptoms of meningitis (e.g., fever, headache and a stiff neck), encephalitis (e.g., drowsiness, confusion, sensory disturbances, and/or motor abnormalities such as paralysis), or meningoencephalitis. Morbidity is age-dependent, and is highest in adults who have developed encephalitis [19]. A third of patients have long-lasting sequelae, frequently with cognitive dysfunction and substantial impairment in quality of life. In general, mortality is rare, about 1–2%, with deaths occurring five to seven days after the onset of neurological symptoms in European TBE. There is no specific drug therapy for TBE; however, effective vaccination is available in some TBE-endemic areas [20].

Tick-borne encephalitis is caused by the tick-borne encephalitis virus (TBEV), a member of the family *Flaviviridae*, and was first isolated in 1937. Three virus sub-types have since been described: European or Western tick-borne encephalitis virus, Siberian tick-borne encephalitis virus, and Far Eastern Tick-borne encephalitis virus (formerly known as Russian Spring Summer encephalitis virus). Ticks, specifically hard ticks of the family *Ixodidae*, act as

both the vector and reservoir for TBEV. The main hosts are small rodents, with humans acting only as accidental hosts. Large animals serve as feeding hosts for the ticks, but do not play a role in maintenance of the virus.

Tick-borne encephalitis has a patchy spatial distribution of endemic regions across Europe, where climatic and ecological conditions are suitable for circulation of the virus. Various models suggest that as the climate warms, a dramatic range expansion of *Ixodes* ticks and tick-borne diseases can be expected [21]. Sports and leisure interests can also expose people to *Ixodes* tick-bites and these have contributed to the increase in the number of TBE cases, despite availability of an effective vaccine. Landscape management patterns, typically those related to the use of forest resources, are becoming increasingly important in explaining contrasting national epidemiological outcomes [22, 23].

A study conducted in 2005 found no evidence of a TBEV reservoir in ticks or wildlife in the Netherlands [24]. While incidence of TBEV-infected ticks has been documented in almost all countries in central and eastern Europe since 1980, and has recently become more common in central Germany, an RIVM Infectious Disease Bulletin from 2006 reported that TBEV was expected to spread to Scandinavia, not to the Netherlands [25]. Before the human cases in July 2016, TBE had occurred in the country only among Dutch travellers to affected areas [26].

The two confirmed TBE cases: key events and timeline

In July 2016, the first autochthonous case of TBE was diagnosed in the Netherlands, five days after a report was published and circulated to medical specialists indicating that TBEV had been found in ticks in the country [27]. A person in their 60s, without recent travel history, showed neurological symptoms after a tick bite, with confirmed TBE on 6 July 2016. The virus was recovered and showed strong homology with the common TBEV-EU strains that cause disease in Europe. The infection probably occurred in a forested area between Driebergen and Maarn, in the province of Utrecht. There was no link to the Sallandse Heuvelrug region, in the province of Overijssel (region Twente), which was at that time the only region in the Netherlands known to harbour TBE-virus-infected ticks. During clinical observation, the patient gradually improved, with no focal neurological deficits present at discharge (day 37), but fatigue and mild subjective cognitive complaints persisted.

A second autochthonous Dutch TBE case was discovered on 14 July 2016 in a 44-year-old male patient, and confirmed on 21 July [28]. By Day 9 the patient had improved, although tinnitus persisted. This is the first described case of TBE associated with the Sallandse Heuvelrug region. Definitive evidence that the infection was caused by the specific TBEV-EU strain from that region is lacking.

Shortly afterwards, a potential third case was found from the region Twente. However, this patient had also been in Germany during the incubation time, which makes it possible that infection occurred there.

Annex 2. Questions for the interviews and focus group discussions

Two sets of questions are given below: one for interviews with institutional representatives, and the other for focus group discussions with the community. The questions are concerned with community-institutional synergies in the context of the two cases of Crimean–Congo haemorrhagic fever (CCHF) that occurred in Spain in 2016, or the two cases of tick-borne encephalitis (TBE) that occurred in the Netherlands, also in 2016.

Interview questions for institutional representatives

Part 1: Mapping the different stakeholder/interest groups

1. Please tell us how you and the institution you work for have been or are involved with Crimean–Congo haemorrhagic fever (CCHF)/tick-borne encephalitis (TBE).

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

Pre-incident phase

2. Has your institution produced any protocols, guidelines, or information leaflets for the population regarding the prevention of tick-borne diseases? [Obtain copies if possible]

3. To what extent were there any public health preparedness activity or simulation exercises, consultations, or training activities involving both the community and the administration prior to this case? Please describe these. Do you consider these activities to have been (a) necessary, and, if so, (b) sufficient? If not, what could have been done in addition?

4. [FOR NATIONAL LEVEL RESPONDENTS] In general, do you think that the community trusted the public health and scientific administration prior to the event? [FOR AUTONOMOUS-COMMUNITY/REGIONAL-LEVEL RESPONDENTS] In general, do you think that the community trusted the public health and scientific administration prior to the event? [FOR ALL RESPONDENTS] Had there been any specific events (such as other disease outbreaks) that promoted or undermined trust? Details.

Incident phase

5. [FOR NATIONAL-LEVEL RESPONDENTS] Were there sufficient numbers of dedicated professional staff able to respond to the case? [FOR AUTONOMOUS-COMMUNITY/REGIONAL-LEVEL RESPONDENTS] Were there sufficient numbers of dedicated professional staff able to respond to the case? [FOR ALL RESPONDENTS] Were there any problems, for example with funding, that may have limited the response?

6. Was there any official guidance for the administration 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 in relation to 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 administration during the response to this event [i.e. shared/transparent/top-down?] Were there any aspects that could have been improved?

10. To what extent do you think different groups who could have been at risk within the community (e.g. hunters, farmers, mountaineers and hikers) cooperated with each other during the response to this event? Examples?

11. Do you think there were 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 [PROBE: for example, undocumented migrants working on farms]? What efforts, if any, were made to reach out to them with information about prevention and, if necessary, treatment-seeking behaviour? Who led these efforts, and what lessons could be learned from this?

Post-incident phase

13. Was there any sort of post-case review of the event, specifically with reference to the ways in which the community and the administration communicated and collaborated together? If so, what form did the review 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 rate (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. [ONLY FOR AUTONOMOUS-COMMUNITY/REGIONAL- LEVEL RESPONDENTS] In general, how do you feel the community and the administration 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?

Focus group discussion questions for representatives of different interest groups within the community

Part 1: Issues arising during each of the three phases of the public health event

Pre-incident phase

1. Public health preparedness exercises are sometimes held in order to raise awareness of a particular public health problem among the different groups of people who may be affected, or who may be part of any response activities.

- Are you aware of any sort of public health preparedness or simulation exercises or training activities that your interest group (hunters, farmers, hikers etc.) has participated in, either on tick-borne diseases or on any other health threats?
- If so, do you consider the activities to have been useful? Why/why not? Is there any way that they could have been improved to make them more useful for you?
- If not, do you consider that public health preparedness exercises would, in principle, be useful? Do you think that people would be interested and available to participate?

2. In general, do you think that the community, and in particular your own interest group, trusted the public health and scientific administration in Castilla Leon prior to the event? Had there been any specific events (such as other disease outbreaks) that promoted or undermined trust? Details.

Incident phase

3. Were the key actors in the community, and in your own interest group, clearly identified and available when the CCHF/TBE case first appeared? To what extent was there clarity about who was expected to do what?

4. From where did people in your interest group receive 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?

5. How was the communication and coordination between people in your interest group and the administration during the response to this event? [i.e. shared/democratic/top-down?]. Were there any aspects that could have been improved?

6. To what extent did different interest groups cooperate with each other during the response to this event? Examples?

7. Do you think there were any groups in the community who, for any reason, were excluded from the response, but who should have been included? Details.

8. Were there any hard-to-reach or vulnerable groups [PROBE: for example, undocumented migrants working on farms]? Are you aware of any efforts that were made to reach out to them with information about prevention and, if necessary, treatment-seeking behaviour? Who led these efforts, and what lessons could be learned from this?

Post-incident phase

9. Was there any sort of post-case review of the event, specifically with reference to the ways in which different interest groups and the administration communicated and collaborated together? If so, what form did this review take, who was involved, and what was the outcome?

10. How much awareness do you think there currently is within your interest group about this event? Do you think that lessons have been learned by your interest group regarding prevention and response practices for future events of this nature?

Part 2: Overview

11. Overall, how would you rate (i) the response of your own interest group and (ii) the official response to the event? Were you satisfied, or do you think some aspects could have been improved?

12. In general, how do you feel your interest group and the administration 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?

13. 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?

14. Is there anything else you would like to add?

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