



## **TECHNICAL REPORT**

# **Synergies in community and institutional public health emergency preparedness for tick-borne diseases in Spain**

**A case study on Crimean-Congo  
haemorrhagic fever**

**ECDC TECHNICAL REPORT**

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A case study on Crimean-Congo haemorrhagic fever



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

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## Abbreviations

AC	autonomous community
CCAES	Coordination Center for Health Alerts and Emergencies
CCHF	Crimean-Congo Haemorrhagic Fever
CCHFV	Crimean-Congo Haemorrhagic Fever Virus
ECDC	European Centre for Disease Prevention and Control
EEA	European Economic Area
EU	European Union
EVD	Ebola Virus Disease
FEMP	National Federation of Municipalities and Provinces
ICU	intensive care unit
OIE	World Organisation for Animal Health
PPE	personal protective equipment
SOP	Standard Operating Procedures
TESSy	The European Surveillance System

# Executive summary

## Background

Within the broad context of EU Decision 1082/2013/EU on serious cross-border 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. The premise for the project is that affected communities are increasingly being recognised as key resources that can be used during public health emergencies, and that the concerns, understanding and experience of ordinary people should be harnessed as an important part of the response.

The aim of this case study project is to identify good practices related to community preparedness for tick-borne diseases. This report focuses on two cases of Crimean-Congo Haemorrhagic Fever (CCHF) that emerged in Spain in August–September 2016, the first autochthonous clinical cases of CCHF in south-western Europe. 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 CCHF;
- to identify inter-sectoral collaboration between health and non-health-related sectors with regard to tick-borne diseases, such as CCHF;
- to identify actions that could be taken by other EU countries.

## Methods

A case study approach was taken for this project, based on three qualitative sources of evidence: documents; interviews with a range of technical experts working at national and autonomous community level; and focus group discussions with community representatives. The latter included people at risk of tick bites (such as hunters, farmers, hikers, veterinarians, and national park workers) and people at risk of nosocomial transmission in healthcare settings. Nine interviews involving a total of 13 individual experts (some interviews included two people) and three focus group discussions involving a total of 15 people were conducted during a visit to Spain by the research team 13–17 November 2017. The data were subjected to thematic analysis in NVivo software and within the framework of a theoretical preparedness cycle that includes the pre-incident, incident, and post-incident phases.

## Findings

### The two CCHF cases

The index case was an adult male who had been hiking on 14 August 2016 in Ávila province, Castilla y León Autonomous Community (AC), which is where he most likely became infected through contact with a tick. He fell ill on 16 August and was admitted to hospital on 18 August in Madrid; he died on 25 August. Since he died without a diagnosis of CCHF, (the disease had not been reported in Spain before and the infected man did not have a travel history to endemic areas), no specific infection control measures were taken, beyond standard procedures, to protect the family members, health workers and laboratory technicians with whom he or his biological samples could have had contact prior to his death.

The second CCHF case was a female health worker who had taken care of the index case while he was in the intensive care unit between 19 and 23 August 2016. She developed symptoms herself on 27 August, recognised that she had the same condition as the index case, and was diagnosed on 31 August, the same day that as the retrospective diagnosis of the index case. She survived and was released from hospital in good health on 19 September 2016.

### Pre-incident phase

The primary stakeholders who were prepared for a zoonotic public health event – even if they were not prepared specifically 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 link to the community at risk of tick bites). Links between these four sets of stakeholders were well-established and built on clearly defined protocols, and this also applied to health workers at risk of potential nosocomial infection. By contrast, pre-existing links and synergies between the authorities and the community at risk of tick bites were limited to contacts with hunters and farmers through the veterinarians.

Protocols and standard operating procedures did not exist in Spain specifically for CCHF before the occurrence of the two cases. However, the country had experience of both imported and autochthonous cases of Ebola during 2014–15, so protocols for dealing with viral haemorrhagic fevers were available and widely known within the health sector.

### Incident phase

A degree of confusion during the first 48 hours after the two CCHF diagnoses led to failures in the information exchange system that had been set up in advance between the Ministry of Health, the public health authorities and communications teams in the two affected Autonomous Communities, and health workers. Some technical experts were informed of the incident by journalists before official channels communicated with them, and operational teams in at least one of the Autonomous Communities also found it necessary to communicate via an unofficial, parallel system during this early stage. However, once the facts became clearer, the communications protocols were properly implemented throughout the rest of the incident phase.

Contact follow-up was successfully conducted, with quite different approaches in the two affected communities. The 400 health workers and laboratory technicians in Madrid Autonomous Community who had potentially had contact with the index case or his biological samples were, by definition, connected to the health system, which meant that the follow-up process could be managed through professional channels. Following up the six family member contacts in Castilla y León Autonomous Community required a more personal and strongly collaborative approach.

The flow of information regarding the incident to the wider community through the media was managed in accordance with protocols that had been developed based on lessons learned during the Ebola crisis in 2014–15, when both imported and autochthonous cases were hospitalised in Madrid. Key principles included predictability in the timing of information release, transparency about what was known and not known, use of recognised and respected spokespersons, and working on the basis of a mutually trusting relationship between communications teams and individual journalists. Some effort was made by the authorities to monitor social media to gain a good understanding of community perceptions of the incident – these efforts detected no significant concerns.

Most media coverage occurred during the first week after the initial CCHF diagnosis, and it was, for the most part, factual and accurate, reflecting the regular information updates received from the authorities. The community was advised through these updates to be alert but not alarmed, and this advice was followed by most people. There was a slight increase in the numbers presenting to their doctors to have ticks removed, but only 41 calls were logged to a CCHF hotline run by Madrid Autonomous Community over a period of 31 days, indicating a low level of concern in the wider population. This relatively limited concern extended to people living in Castilla y León who were potentially at risk of bites from CCHF-infected ticks. The main preoccupation in the village from which the index case originated was not the risk of infection, but rather the media intrusion in the days immediately after the diagnosis. For many people in this area, ticks are a regular part of life, and they have extensive experience of being bitten, as well as a good knowledge of preventive practices.

Somewhat more concern was expressed among potentially at-risk health workers who, in one of the Autonomous Communities, were worried about the level of protection available to them should they encounter a CCHF case. A new protocol was swiftly developed by the Autonomous Community authorities to address this concern, which reflects both the capacity of the health workers to stand up for their right to be protected, and the willingness of the authorities to listen to their employees' concerns. However, it is important to note fact that the authorities were also reportedly worried about legal and insurance issues, as well as union pressure, which would probably also have played a role in their decision to revise the protocol. Therefore, although there was a synergistic, bi-directional relationship, the motivation on both sides could have been partially due to the need for self-protection.

### Post-incident phase

No formal evaluation or overall post-incident review was conducted after the CCHF cases. This systemic shortcoming was ascribed to limited finances, human resources and time, as well as the wider organisational culture within the Ministry of Health and the two Autonomous Communities. As a result, it is unlikely that any successful synergies or collaboration that may have emerged, or other lessons learned will have been formally documented for future reference.

However, informal evaluations were carried out at both national and Autonomous-Community level on a number of discrete issues, and changes were made to various SOPs and protocols. These included: (i) implementation of a tracking system at the reference laboratory to facilitate *post hoc* identification of people who have handled specific biological samples; (ii) the addition by the Ministry of Agriculture of CCHF to their ongoing surveillance system, which reflects 'One Health' thinking; and (iii) publication on the Autonomous Community and Ministry of Health websites of updated information on ticks, tick-borne diseases, and tick removal.

## Good practices and lessons learned

This study details a set of 13 good practices for promoting collaboration and synergies between the authorities and the community, as well as four other key lessons learned. In the list below, we have identified the good practices specific to tick-borne diseases (T), other zoonoses (Z), and/or to public health threats more generally (PH). Each of these points was suggested to us by one or more of our informants.

- Promoting inter-sectoral collaboration and synergies between the authorities
  - Implement a multi-sectoral tick surveillance programme, with activities integrated between the Ministry of Health and the Ministry of Agriculture (T, Z).
  - Conduct multi-sectoral simulation exercises, including key stakeholders at national, Autonomous Community and local levels (PH).
- Promoting collaboration and synergies within the health sector
  - Develop a protocol, in advance of any public health incident, to establish a crisis committee and identify a spokesperson to represent the authorities (PH).
  - Ensure efficient and smooth information exchange within and between key health sector institutions, including public health agencies at both national and Autonomous Community levels, healthcare facilities, and laboratories (PH).
- Promoting collaboration and synergies between the authorities and the community
  - Adopt different approaches as appropriate when following up different categories of potentially exposed contacts in the community (PH).
  - Use pre-existing connections with the community and local organisations to effectively disseminate information to people who may be at risk of tick-borne or other zoonotic diseases (T, Z).
  - Provide feedback to community members who contribute to surveillance and other preparedness activities by, for example, collecting and sending in ticks (T, Z).
  - Ensure that systematic efforts are made to monitor community perceptions of any public health incident (PH).
  - Recognise the rural-urban divide in perceptions regarding tick-borne diseases when designing communication strategies and targeting messages (T, Z, PH).
  - Ensure that risk communication messages reach people who could be considered vulnerable to infection, but who may not easily receive or access information about prevention. This could include people who do not speak Spanish and who may therefore need translated materials (PH).
  - Use occupational health specialists as a valuable resource for dissemination of information on prevention for specific, at-risk professions, and as a key support for contact tracing and follow-up activities (PH).
  - Build trusting relationships with journalists prior to the crisis (PH).
  - 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 (Z, PH).
- Other important lessons learned
  - Introduce evaluation activities into standard operating procedures, and establish the practice of sharing experiences and lessons learned between stakeholders in different sectors at various levels (PH).
  - Verify that haemorrhagic fever protocols have been updated after the 2014–15 Ebola crisis (PH).
  - Establish tracking systems for biological samples in reference laboratories (PH).
  - Train triage and primary care nurses to be on the lookout for unexpected and potentially dangerous infectious diseases, for the purposes of rapid diagnosis and initiation of appropriate public health measures (PH).
- This study has demonstrated the potentially substantial value to be gained by building cooperation between health and non-health sector authorities and the community in the prevention and control of zoonotic diseases in Spain. Goodwill and a willingness to work together was apparent from all the stakeholders interviewed, but any successful long-term collaboration will require significant ongoing efforts, planning, and resources.
- Consideration could be given to focusing future operational research on how best to implement and sustain the good practices identified above, and how to develop additional methods for effective community-authority collaboration in preparedness and response to zoonotic diseases. This 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 1082/2013.



# 1. Background, context and definitions

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 [12]. 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<sup>1</sup>, 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.

The present report is concerned with the events in Spain surrounding two cases of infection with Crimean-Congo Haemorrhagic Fever (CCHF) virus that emerged in the Autonomous Community of Castilla y León in August 2016<sup>2</sup>. The index case died while the second case – a health worker who attended the primary case while he was admitted to an intensive care unit at a Madrid hospital – survived. These are the first autochthonous clinical cases of CCHF diagnosed in Spain and in south-western Europe.

## Crimean-Congo haemorrhagic fever

CCHF is endemic throughout much of southern and eastern Europe, the Middle East, Africa, and Asia. Turkey is one of the most affected countries in the world, although a good surveillance system has been established in the country which has lowered the case fatality rate since the first cases were detected in 2002. High levels of awareness, both in the community and among health workers, facilitates the early detection of individual CCHF cases which can significantly reduce fatality rates [3]. 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) [4, 5]. No other EU/EEA countries reported cases that year [6]. The disease's expanding global incidence is probably the result of climate and environmental changes. 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 is an ongoing debate about its efficacy. Commercial assays for CCHF genome detection exist, but confirmation by additional assay is needed [7] [8].

Since CCHF is one of very few tick-borne diseases that can be transmitted from human to human, specific efforts are required to control its spread in healthcare settings, in particular from infected patients to the health workers caring for them. A study conducted in medical units in twenty-three countries across the continental landmass of Europe and Asia found that there was, at least in theory, a high risk of nosocomial CCHF transmission 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 required in relation to disinfection of medical environment, waste management, and PPE use [9].

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. Travelers 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 [10].

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,

<sup>1</sup> Previous ECDC cases studies on institutional preparedness focussed on Ebola [17], MERS [18] and polio [19]

<sup>2</sup> Parallel work in the Netherlands focused on tick-borne encephalitis and Lyme borreliosis and is the subject of a separate report.

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 [6].

### Spanish healthcare system

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.

### Definitions

There are three key terms that have been used over the course of this case study project which 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'.
- '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' [11].

## 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 Spain was to collect evidence and identify good practices related to community preparedness for public health emergencies in the EU. 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 to other EU Member States in the short and longer term.

## 3. Methods

### 3.1 Study design and participants

A case study approach was taken for this project, which was based on three qualitative sources of evidence: documents; interviews with a range of experts working at national and Autonomous-Community level and focus group discussions with community representatives. We chose to conduct interviews with the experts in order to allow for in-depth discussion of their professional perspectives and experiences, while the focus group discussions were conducted to develop insights into community norms and values relating to the topic. The interviews and focus group discussions were conducted during a visit to Spain by the research team in the week of 13–17 November 2017.

The interview and focus group discussion participant categories, agreed upon in close collaboration with ECDC and the Spanish counterparts (based at CCAES), were as follows:

Central administration at national level (expert interviews)

- Ministry of Agriculture, Fish, Food and Environment
- General Directorate of Public Health
- Press cabinet/journalist.

Madrid Autonomous Community (expert interviews)

- Public health authority
- Environmental and animal health
- Press cabinet or communication to the Citizen's Office.

Castilla y León Autonomous Community (expert interviews)

- Human public health
- Animal public health
- Communication to the Citizen's Office.

Madrid Autonomous Community (Community focus group discussion)

- Occupational Hazards Unit
- Emergency room clinicians
- Local human public health services
- Central human public health services
- Human public health emergency team
- Veterinary health emergency team.

Castilla y León Autonomous Community (Community focus group discussion with people who are occasionally at risk of exposure to ticks)

- General population
- Hiker
- Hunter
- Veterinarian (focused on hunter activity).

Castilla y León Autonomous Community (Community focus group discussion with people who have a permanent/ongoing risk of exposure to ticks)

- Veterinarian (focused on livestock)
- Farmers
- Livestock farmer
- National park worker.

Table 1 below presents an overview of the interviewees and focus group discussion participants who contributed to the study.

**Table 1. Number of interviews and focus group discussions, and respective numbers of participants at national and Autonomous-Community level**

	Health sector interviews (no. of participants)	Non-health sector interviews (no. of participants)	Community focus group discussions (no. of participants)	Total number of participants
National level	1 (2)	2 (4)	-	6
Madrid AC	1 (1)	2 (2)	1 (6)	9
Castilla y León AC	1 (2)	2 (2)	2 (9)	13
<b>Total no. of participants</b>	<b>5</b>	<b>8</b>	<b>15</b>	<b>28</b>

## 3.2 Data Collection

### Documents

Background materials on CCHF, including material from other settings where the disease is prevalent, and from Spain itself, were identified through online searches. The major points are summarised in Section 4.1.

Prior to the country visit, the Spanish representatives from CCAES sent press cuttings collected during the 2016 CCHF event, clips of relevant TV news stories and links to official websites for tick-borne diseases. These sources, which provided an invaluable overview of what had happened and how the public and the media had responded, are summarised in Section 4.2.2 in the section entitled 'Managing the media'.

Additional documentary materials were collected from interviewees and during focus group discussions while visiting Spain. The content is used as supporting text in 'Findings' (Section 4).

### Interviews and focus group discussions

An initial set of questions for the interviews and 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 [12]. The questions were structured in the format of a theoretical preparedness cycle, based on pre-incident, incident, and post-incident phases [13,14]. They were then adapted based on comments received from ECDC and the Spanish counterparts. The final version of the questions is presented in Annex 2. In order to facilitate the interview and focus group discussion process, the questions were translated into Spanish and sent in advance to the participants to allow them to prepare.

The questions were designed to be broadly relevant to all interviewee categories, but the focus varied according to the position and particular experience of each individual interviewee or focus group.

The national-level interviews were conducted at the Ministry of Health and the Ministry of Agriculture, while the Autonomous-Community interviews and focus group discussions were conducted at the Madrid Autonomous Community and Castilla y León Autonomous Community offices. Interviewees and focus group discussion participants were recruited by the CCAES team and the contact point for the study identified in the Autonomous Communities. The CCAES coordinated the activities, organised the week's agenda and dealt with the main logistical issues<sup>3</sup>.

## 3.3 Ethical considerations

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

## 3.4 Ethical analysis

The notes from the interviews and focus group discussions were subjected to thematic analysis, using NVivo qualitative data software. A set of pre-defined codes was used as a starting point, based on the questions in the interviews, with additional codes included as they emerged inductively. The analysis was conducted within the context of the theoretical preparedness cycle [13, 14]. 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 identification of lessons learned. We also distinguished between national and provincial/Autonomous-Community levels in the analysis.

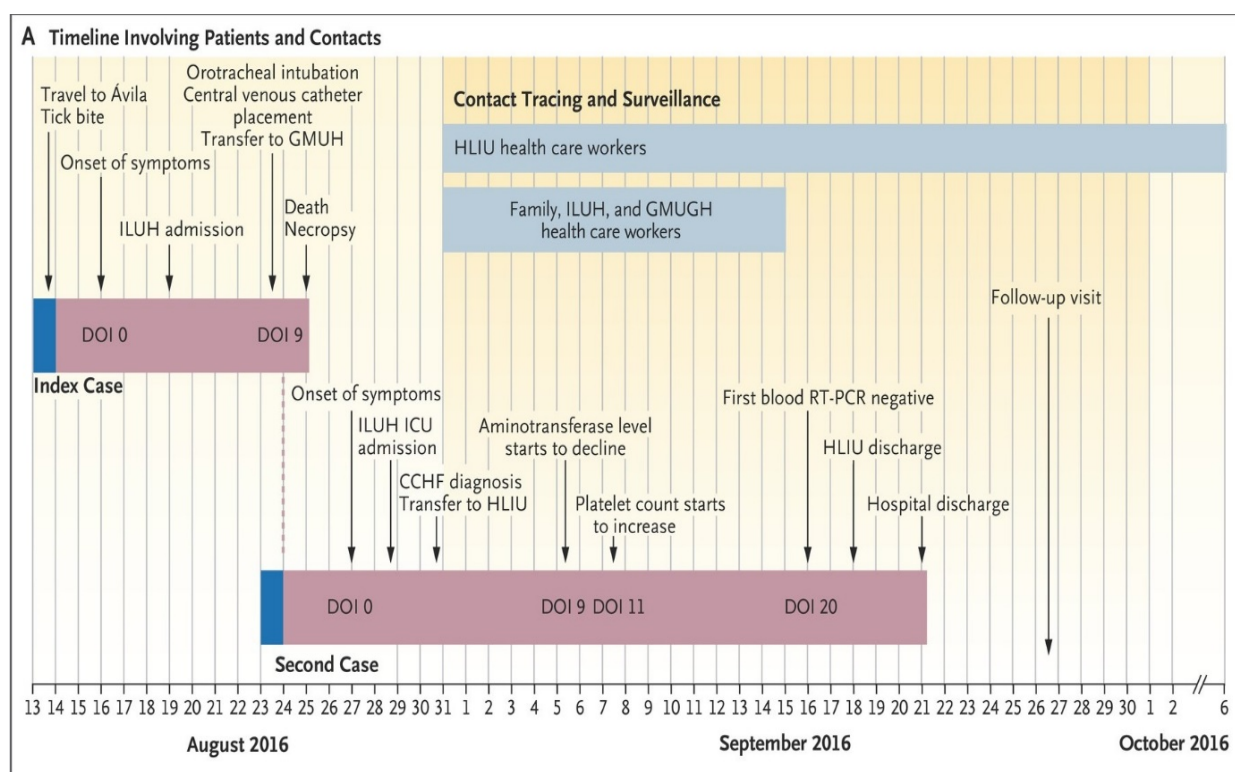
<sup>3</sup> A senior expert (JK) from Umeå University's PREPARE consortium conducted the interviews in English, with translation support where needed. He was supported by a junior scientist (JA) who took notes and observed the discussions. Two ECDC staff (Svetla Tsolova and Hervé Zeller) provided introductions and technical support for the first two days of the country visit, while another ECDC staff member (Andrea Würz) provided essential interpretation throughout the visit, moderated the focus group discussions in Spanish and contributed with expertise in communication issues. Simultaneous interpretation of the focus group discussions into English was provided by Lidia Redondo, courtesy of our hosts from CCAES, and English language notes were then taken from this. We were accompanied to each interview and focus group discussion by either Fernando Simon or Berta Suárez Rodríguez, senior staff members of CCAES.

## 4. Findings

### 4.1 The two CCHF cases: key events and timeline

The index case was an adult male who had been hiking on 14 August 2016 in Ávila province, Castilla y León Autonomous Community, where he probably 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 Leonor Hospital in Madrid on 19 August. He was then transferred to an isolation ICU at 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 no specific infection control measures were implemented, beyond standard procedures, to protect the family members, health workers, and laboratory technicians with whom he or his biological samples 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.

**Figure 1. Timeline of the two CCHF cases in Spain, 2016 [15]**



Note: Dark blue denotes the day of infection for each patient; DOI denotes day of illness; GMUGH denotes Gregorio Marañón University General Hospital; HLIU denotes high-level isolation unit; ICU denotes intensive care unit; ILUH denotes Infanta Leonor University Hospital.

The second CCHF case was a female health worker who had taken care of the patient in the ICU between 19 and 23 August 2016. She developed symptoms 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 that she had cared for and she mentioned this to her doctors, the connection between the two individuals was finally 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 31 August 2018. See Figure 1 for a timeline of the two cases.

## 4.2 Synergies and connections in the three preparedness cycle phases

### 4.2.1 Pre-incident phase

Prior to the incident little or no work had been done in preparation for CCHF in Spain: this was an unexpected event. However, a number of pre-existing contextual factors, both facilitators and inhibitors, significantly influenced the response to the cases when they emerged. These factors specifically related to ticks and tick-borne diseases (in both the human and animal health sectors), as well as issues that were unrelated but which still had an impact on the way the event was perceived and addressed by different stakeholders.

#### *Facilitating factors*

##### **Protocol for identifying a spokesperson during a future event**

An important decision that had been made prior to the CCHF event concerned the public face that Madrid Autonomous Community would show in any future public health emergency or event. It had been agreed that a respected scientist would represent the Autonomous Community and its positions relating to the situation in any media briefings. This decision was based on lessons learned during the 2014–15 Ebola crisis.

##### **Protocol for crisis management committee**

Decisions had also been made in Madrid Autonomous Community regarding the activities of any future crisis management committee. The committee would include all key participating partners (Ministry of Health, universities, Autonomous Community representatives and communications experts working with the authorities), and it would hold regular meetings during the event. This protocol was followed when responding to the CCHF cases.

##### **Tick surveillance**

Tick surveillance has been ongoing in Spain for 25 years, and intermittently for CCHF since 2009, therefore an infrastructure was already in place before the 2016 event. The surveillance system works 'downwards', via the Ministry of Agriculture to the Autonomous Community veterinarians and the hunters in the field who are responsible for collecting and sending in tick samples. It also works 'upwards', from those involved in analysis of the samples and the epidemiologists, who send their findings to decision makers in the Ministry of Health and the Autonomous Communities, to hospitals, and also on to international organisations such as the World Organisation for Animal Health (OIE) and the EU's European Food Safety Authority.

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, and other relevant stakeholders are also involved, through a formalised and well developed system.

Consequently, after the CCHF cases were identified in 2016, the system was fully prepared to respond rapidly with an enhanced surveillance programme. To date, no CCHF virus has been identified in Castilla y León where the index case is believed to have been bitten and infected (even since surveillance was stepped up in late 2016). However, if the virus is identified either in ticks or in animals, prevention messaging can be intensified in the specific areas where it has been found.

##### **Impact of the Ebola crisis 2014/15**

Some elements of the Ebola experience had a positive effect on preparedness activities in Spain, while other elements acted as inhibiting factors (see below). From a positive point of view, the CCHF event demonstrated that lessons learnt from Ebola had been identified, and many institutional crisis response plans had been updated. These included protocols for viral haemorrhagic fevers at national level, which could easily be adapted at Autonomous Community level. For example, the protocols helped to improve coordination between epidemiologists in the field and the hospitals and/or authorities in the Autonomous Community. They also facilitated the CCHF contact tracing process, since the interview forms used when following up CCHF contacts were based on the Ebola contact tracing documents.

As a result of the simulation exercises that were held in many Spanish hospitals during and after the 2014–15 Ebola crisis, health workers in the country are, in general, more knowledgeable now about handling patients with serious infectious diseases (for example using PPE). The capacities of the country's reference laboratories were also enhanced through the Ebola experience. In broad terms therefore, the structures are in place, and people know who to contact in the event of an emergency.

Another key area where benefits from the Ebola experience have been felt was in communications. There was consensus among our interviewees that communications during the early stages of the Ebola crisis in Spain were poor, but that considerable improvements were made over the course of the crisis in coordination, strategy, and implementation. No formal evaluation of communications was conducted post-Ebola, but lessons were nonetheless

learned informally, and this had positive implications for the way communications were handled during the CCHF event. In the community, memories of Ebola – and specifically of the Spanish nurse who was infected with Ebola and who attracted a lot of media attention in the country – reportedly also made people less likely to over-react to CCHF, so the population response to the event was quite muted.

#### **Awareness of ticks in highly exposed communities**

Several of our focus group discussion participants – farmers, hunter, veterinarian and national park worker – reported regular exposure to ticks during their daily activities; and while we cannot say that they were necessarily representative of their peers, it would seem likely that these groups are, on the whole, well aware of the issue. One farmer spoke of a time when he removed as many as 20 ticks from his body at the end of a working day; and the hunter talked about the ongoing need to remove ticks from his dogs. By contrast, hikers – a heterogeneous group with little formal organisation and much less regular exposure to ticks – were seen as less knowledgeable about prevention of tick bites and tick removal. However, although these participants indicated that ticks are somewhat inconvenient, they were not seen as a major problem by any of them.

#### ***Inhibiting factors***

##### **Impact of the 2008 economic crisis**

All respondents in official positions spoke of the severe impact of the 2008 economic crisis and subsequent austerity measures on their work. The most frequently cited problem at both national and AC level was the inability to recruit new staff, which meant that fewer people were available to do the same amount of work. Even with an economic upturn in Spain challenges remain, although thanks to multi-tasking and hard work, the core public health services do remain intact and functional.

##### **Political context**

At the time of the CCHF cases in 2016, Spain did not have a Health Minister appointed to the post. The Minister of Social Work was placed in charge of the response. Some of our interviewees indicated that this created challenges with regard to coordination.

##### **Impact of the Ebola outbreak 2014/15**

Ebola had a negative impact on the CCHF event in two broad areas. At the political level, we were informed that several high-level politicians had been dismissed after the Ebola crisis because of their handling of the situation. Thus there could have been a degree of anxiety in the minds of some political actors during the CCHF event. Consequently, they wanted to manage the flow of information during the critical first 48 hours of the event, and this led to delays in the sending of essential information to people at operational levels. On this occasion, there was no further spread of the virus, so there were no serious consequences as a result of this lack of information. However, the situation could have been quite different with another pathogen or epidemiological context.

At the level of individual health workers, there was a residual fear of viral haemorrhagic fevers because of Ebola, which made some people reluctant to engage with patients deemed to be at risk of CCHF. Hospitals had different standards of personal protection – with some designated high-level isolation units clearly much more advanced than others – and this made some health workers in the less well-equipped facilities wonder why they also did not have the best protection available. The fact that CCHF does not require the same level of protection as, for example, Ebola, and therefore that the most sophisticated PPE may not be necessary when treating CCHF patients, did not placate all of those who felt that they had 'lower' levels of protection.

##### **Low awareness of serious tick-borne diseases among health workers**

The fact that the index case had already died – with a diagnosis of liver failure brought on by hepatitis – and been buried before he was diagnosed with CCHF is a potential matter of concern. This type of delay in diagnosis points to a significant gap in the response that needs to be acknowledged and addressed. The delay may be at least partially explained by the fact that, as we were told, the work during and after the Ebola crisis in the country placed a clear focus on the likelihood of imported rather than autochthonous cases of viral haemorrhagic fevers (even though there had been one autochthonous case of Ebola in a Madrid-based health worker who had been caring for a repatriated EVD case in October 2014). The potential for autochthonous cases of viral haemorrhagic fevers therefore needs to be incorporated more fully in future preparedness planning.

## **4.2.2 Incident phase**

### ***The events of 31 August - 1 September 2016***

There were three major official actors involved during the course of the CCHF event. The Ministry of Health at national level; Madrid Autonomous Community, where both cases had been hospitalised and where most of the follow-up and communications were therefore required and Castilla y León Autonomous Community, where the index case was believed to have been infected. Therefore, at the official level, there was essentially a triangle of communications between these three actors.



### National level

As soon as the diagnosis of CCHF was confirmed in the reference laboratory on 31 August 2016, the General Directors of the Ministry of Health and the Public Health departments in both Madrid Autonomous Community and Castilla y León Autonomous Community were informed. However, the information did not reach the Ministry of Health communications team before journalists started to call and they were therefore alerted to the situation by outside sources.

Although we learned that subsequent internal coordination within the Ministry regarding CCHF was good, there was a misunderstanding during the first 24 hours after diagnosis regarding the village where the index case had come from. There are two villages 100 km apart in Castilla y León with the same name, both of which are quite isolated, and the information from Madrid Autonomous Community initially identified the wrong village as the source. Consequently, the media appeared at the wrong place – though this did have the advantage of allowing the family of the index case more time to prepare themselves. Furthermore, the Ministry of Health communicated the wrong village to the Castilla León public health authorities, who then made contact with the wrong health centre regarding the case – the man had never been treated there. In terms of the disease itself, the misidentification of the village had potential implications in developing hypotheses regarding transmission. Migratory birds from Africa were initially thought to be the source of the virus, since a particular species reportedly flies over this village. However, when it emerged that the source was the other village, which these birds do not cross, further hypotheses were considered, in particular the possibility that the virus may have been brought in by animals being transported between hunting reserves, and possibly from Extremadura Autonomous Community.

### Madrid Autonomous Community

As soon as the diagnosis was confirmed, the Madrid Autonomous Community public health authorities created a crisis committee in accordance with their protocols. In the beginning, regular meetings were held (daily), until the second case had recovered and was discharged from hospital.

The communications team in Madrid Autonomous Community had already been informed of suspected CCHF cases prior to the confirmed diagnosis and they debated among themselves whether to put together a press release immediately or whether to wait until more information became available. After the diagnosis on 31 August 2016, when journalists started to call, a press release was prepared for dissemination the next day, 1 September 2016. Subsequently, a press conference was held at which the situation regarding the two confirmed cases was explained to the media. From that moment, information was provided to the media regularly by the Madrid Autonomous Community communication team. Journalists requesting additional information were referred to these regular updates, partly to keep the press office's workload under control but also to ensure that all parties were treated equally, with no particular newspaper or TV channel receiving preferential treatment.

Madrid Autonomous Community and Castilla y León Autonomous Community were in contact during the first few days, in accordance with the relevant protocols, in order to exchange information on the movements of the index cases and to work on identifying possible contacts. The key public health professionals involved in the two Autonomous Communities have known each other professionally for many years, and this helped to facilitate communication.

**Castilla y León Autonomous Community** The CCHF alert came through the Ministry of Health to the General Director of Public Health in 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 other colleagues through unsubstantiated reports in the media, or directly from journalists who approached them for information that they could not then give. Journalists who contacted the Autonomous Community on 31 August therefore had to be referred to the press office in Madrid Autonomous Community.

A bottleneck was also reported regarding the communication channels between Castilla y León Autonomous Community and Madrid Autonomous Community, which led to the creation of parallel systems. Key aspects of the information exchange process between Autonomous Communities are supposed to be authorised by the general directors, who have political oversight of the process, with some information also passing through the Ministry of Health. However, in this case some important information was not passed downwards. Some technical experts therefore found it necessary to communicate directly with their counterparts. At that early stage, it was not known who had been exposed or the extent of the risk, and they considered it important to rapidly exchange any verified information, in particular to ensure that health workers in the two Autonomous Communities were kept as fully informed as possible.

Once the information about the cases had been circulated within the 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 and reassurances that the risk of infection was low. A link to information on the Autonomous Community website was included, with details of how to protect against ticks and how to remove them. At this stage, it was not known whether there were further undetected cases in the community. This press release stimulated quite a lot of interest from the national media.

### Following up potential contacts

Contact follow-up was a major task, with around 400 people included in the process. There were six people in Castilla y León (all close family members of the index case) and the rest were laboratory workers or health workers in Madrid Autonomous Community, exposed or potentially exposed before the CCHF diagnosis had been made.

Contact tracing and follow-up started in Castilla y León Autonomous Community on 1 September 2016. The approach was based on an operational case definition that had been developed for Ebola, and it included investigations into where the index case had been over the incubation and infective periods, as well as clinical details about the disease and ongoing treatments. The adult daughter of the index case was contacted, and information about other people who could have been exposed – all of them family members – was collected through her. Doctors then visited these six individuals at their homes in order to avoid any possible risk of spreading the virus by their attending a healthcare facility, and they were phoned once a day until the end of the follow-up period to assess any changes in their health. We were told that the family members were very collaborative, in spite (or perhaps because) of the fact that they were in mourning, and the follow-up process proceeded smoothly. The follow-up ended on 9 September, 14 days after their last physical contact with the index case (which is one day longer than the documented maximum incubation period [16]).

The situation was considerably more complex in Madrid, as it was not clear who had been in contact either with the index case himself, the secondary case, or the biological samples taken from them. Consequently, all the workers at the reference laboratory and on the wards where the cases had been treated were deemed to be at risk. A follow-up was also made at the funeral home where the body had been prepared for burial. All the contacts and potential contacts were then placed into a systematic risk classification system. Individuals were put into a set of concentric circles with those closest to the middle considered to be at highest risk, and contacted twice daily for the duration of the 14-day follow-up period. These higher-risk individuals included the health workers who took care of the patients without using the appropriate PPE, in particular in the intensive care unit; and one person from the reference laboratory, who happened to be pregnant. Frequency of contact by the follow-up team was less for those placed in the outer circles. Anxiety was reported among some contacts, but this was for the most part managed effectively. All contacts were cleared after the requisite 14 days of follow-up.

Two important distinctions can be made between the contact follow-up process in Madrid and in Castilla y León. First, the infection of the health worker in Madrid was detected when the follow-up period for the contacts of the index case was already advanced (see Figure 1), which made the active follow-up period for contacts in Castilla y León shorter than the 14 days that were necessary for most contacts in Madrid. Thus, the anxiety of the contacts in Castilla y León was less drawn-out than for those in Madrid. In addition, since the Madrid community included key staff from the reference laboratory that receives biological samples from eight hospitals in and around the city, there was inevitably some disruption to the important diagnostic routines in place there during that period. Delays in the routine testing of biological samples and the returning of results due to limited laboratory capacity were noted by our interviewees, and this was exacerbated by the situation.

Secondly, the affected 'community' in Madrid consisted of people employed by the healthcare system, which meant that the contact tracing and follow-up process went through established official channels between the public health authorities, the reference laboratory, and the hospitals concerned. By contrast, the affected 'community' in Castilla y León consisted of the close family circle of the index case, which comprised only six contacts, so a more personal approach was required.

### Managing the media

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, in general, more interested in covering other issues during this period. Our analysis of several national and regional newspapers (including *El País* and *El Mundo*) identified 45 articles up until 22 September 2016, 23 of which (51%) were published by 6 September 2016, indicating a rapid cooling 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 Madrid Autonomous Community were doing to keep the virus from spreading further.

Most of the official communications on the topic took place in Madrid Autonomous Community as opposed to Castilla y León Autonomous Community, because most of the contacts were health workers or laboratory technicians working in the Madrid Autonomous Community. Key objectives of the communications included ensuring that the community remained calm, and reassuring people that the risk of any further spread of the virus was low. To this end, regular briefings were provided to journalists (once or twice each day) during the period directly after the diagnosis, even if there were no significant updates to report. The briefings always came from the same source, and they included a link to information on either the official Ministry of Health or the Autonomous Community website on how to protect

against ticks and remove them<sup>4</sup>. Face-to-face meetings were also held with journalists to educate them about CCHF and tick-borne diseases, in order to maximise accurate and balanced reporting.

In addition, steps were taken to ensure that the release of information to the media and to health workers and hospitals where people remained under surveillance was coordinated. The Madrid Autonomous Community occupational health team, which was responsible for supporting and informing the health workers, played a critical role in this process. Key actors in hospitals received press releases shortly before the general release, so that they were informed in advance of any possible media enquiries, but all other sources received the information at the same time, thereby avoiding any sense that one group was being privileged over another.

By being predictable and transparent, and by relying on pre-existing and trusting relationships 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, and thereby to avoid 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, samples had not yet been processed). People at community level were aware of the media coverage of CCHF, but – as intended by the authorities – they were not particularly concerned.

### Monitoring social media

Insufficient human resources limited efforts by the authorities to monitor social media in order to ascertain if there were rumours or misinformation circulating in the community, or otherwise to understand community perceptions of the event. The communications team at the Ministry of Health receives alerts from a range of official sources, but not from the community itself. The public health authorities at one of the Autonomous Communities told us that they monitor social media by following specific institutions and hashtags – but it was pointed out that if a keyword is missed, the search may not pick up a point of interest. Rumours may also be reported informally through contacts with journalists seeking clarification or comment on an issue, but this is not a systematic process.

No significant rumours were reported on social media in relation to CCHF, although there was a report on social media that 'Excalibur' – the dog belonging to the Spanish nurse infected with Ebola in 2014, that was controversially euthanised – had at one stage visited the village where the index case was infected with CCHF. The precise implication of this claim was never made clear.

### Community perceptions and response

Madrid Autonomous Community set up a hotline for people to call in order to receive information about CCHF and tick-borne diseases, the only dedicated channel that we heard about for community members to communicate directly with the authorities. The hotline received a total of 41 calls logged between 31 August and October 1, an average of just over one call per day. Although we did not obtain details during our interviews regarding the extent to which the hotline was advertised, and how well it was known throughout the population, the impression from our interviewees was that the small number of calls indicated a muted response to CCHF from the wider community. Since the incident only lasted a few days, there was not really time for concerns to develop to any great extent. However, specific concerns were raised by the two sub-groups which may have had more direct exposure: health workers in Madrid Autonomous Community, and people at risk of tick bites in Castilla y León Autonomous Community.

### Health workers

As soon as CCHF was diagnosed, the public health authorities in Madrid Autonomous Community communicated to all the hospitals under their jurisdiction, telling health workers to stay calm. They clarified that the second case had been caused by the index case's illness going undiagnosed, and that since it was now known to have been CCHF, precautions were in place and the chance of further spread was extremely low. We were told by the authorities that consequently there was 'no real worry' within this community.

However, 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 SOPs and protocols for viral haemorrhagic fevers, was produced as early as 2 September and circulated to the appropriate facilities. This was one of the very first official activities in response to CCHF, and the speed with which it was conducted was at least partially the product of pressure from the health workers themselves.

<sup>4</sup> [http://www.msssi.es/profesionales/saludPublica/enfermedadesEmergentes/Crimea\\_Congo/home.htm](http://www.msssi.es/profesionales/saludPublica/enfermedadesEmergentes/Crimea_Congo/home.htm)

This website includes 1) *General information and recommendations for citizens*: transmission, symptoms, CCHF diagnosis/treatment; treatment-seeking behaviour; prevention & control measures undertaken by the Ministry of Health, Social Services and Equality; surveillance; coordination activities between the human and animal health and the environment sectors; tick removal; control of ticks with repellents and insecticides. 2) *Technical information for health professionals*: risk of CCHF transmission in Spain; surveillance; vector; virulence and lethality; diagnosis; disease development; case notification; contact tracing; hospitalisation and isolation; care with biological samples; protection against infection among health workers.

Concerns were also raised by a number of health workers about the types of PPE available in different healthcare settings. The standards of protection were better at designated high-level isolation units, and those who had what appeared to be less secure equipment complained that they would not be protected as well as their colleagues, in spite of the fact that CCHFV is not easily transmissible from human to human, and that very high levels of protection – such as those used for Ebola – are not really necessary. They argued that the discrepancies reflected a lack of coherence in the planning by the different hospitals. However, it could equally be argued that all the hospitals met the required minimum standards as laid down by the Ministry of Health and the respective Autonomous Community public health authorities, and that hospitals had quite legitimately and legally prioritised different areas. Since there were no further cases, this issue did not become a major problem, but it does point to the importance of hospital leadership communicating clearly to their front-line workers why certain decisions about personal protection may have been made.

#### Individuals and groups at risk of tick bites – Castilla y León Autonomous Community

As indicated above, people who spend a lot of time outdoors in Castilla y León Autonomous Community are used to ticks, and while they are an inconvenience, they do not generally consider them to be a major problem. A national park worker, who is regularly exposed to ticks in her job, said that until the CCHF case emerged, she had never known that tick bites could cause fatal disease. A hunter concurred, saying that while ticks themselves are not a new issue, the diseases that they may transmit, at least to humans, are. (No mention was made during any of the focus group discussions at community level of tick-borne encephalitis, Lyme borreliosis, or tularemia.) The CCHF case has, it appeared, brought about a change in perceptions of the potential dangers of ticks among at least some people who are frequently exposed.

Indeed, during the incident phase, increased awareness of CCHF led to more people with tick bites attending their doctors, and consequently 13 cases of suspected CCHF were reported nationwide during September 2016. In one sense this is positive, as it shows that people – both in the community and among health workers – were sufficiently informed to act on their concerns about the disease. However, it also created challenges with the requirement to immediately activate the expensive isolation units that were needed, unnecessarily as it turned out, for each case.

With regard to people who are less frequently exposed, one of our focus group discussion participants had reportedly visited the village where the CCHF index case had lived, where he heard that the people there were not very worried about potentially being infected themselves. Their main concern was with the media, which had come to interview the family and other inhabitants about the case, and which reportedly caused some disturbance.

Another focus group discussion participant, who said she was only infrequently exposed to ticks, said that she knew the case had been caused by a virus, which she thought had been brought by a migratory bird returning from Africa, but she had not been alarmed at any stage during the incident phase. Since there were no further cases, she said she had more or less forgotten about it. A hiker reported that she always wears long trousers when she goes out, but many of her friends do not: while she understands the issue and takes precautions herself, there are many who do not. 'There is not enough concern within the public for these risks,' she said.

### 4.2.3 Post-incident phase

No substantive evaluation or post-incident review was conducted after the CCHF event. According to our respondents, this was due to limited resources (financial and human) and, according to some insiders, the prevailing organisational culture in the Ministry of Health and the two affected Autonomous Communities. We were told of a special unit for evaluation that had been established in one of the Autonomous Communities shortly before the financial crisis of 2008, but it was disbanded around five years ago. This, we were told, indicated a lack of political interest in prioritising post-event evaluations.

Our interviewees clearly recognised the importance of retaining institutional memory of lessons learned during public health events – for example, as regards communication strategies in a situation of uncertainty – and the need to evaluate during the preparedness and response planning process. As we were told, you can always do better, in particular during the early phase of a situation when uncertainty prevails about the scale of the problem and the risk it presents. In addition, lessons will be learned during a crisis, and there can be great benefit in documenting these properly. However, it was also pointed out that very few countries in Europe have systems in place for substantive post-incident reviews or evaluations, so the situation in Spain is by no means unique.

In spite of 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. A new tracking system was put in place at the central laboratory in Madrid Autonomous Community, so that it is now possible to establish post hoc who may have handled particular biological samples. This measure aims to provide an accurate database of personnel who may need to be followed up after possible exposure to dangerous pathogens.

- CCHF virus surveillance. The Ministry of Agriculture concluded after the event that CCHFV should be added to their regular surveillance protocol – even though CCHF is a problem for human health and not animal health, and strictly speaking it does not therefore fall under their remit. This reflects an important decision to adopt a ‘One Health’ approach, and it also shows that the country has an adaptive surveillance system. However, one of the hunters we spoke with said that he was involved in collecting ticks for some of the studies mentioned in Section 1 above, yet he has never received any feedback regarding their disease status. He would like to be informed of these details, and the fact that he does not receive the results reduces his trust in the authorities.
- Messages about tick removal. Recognising the need for an updated information campaign, new messages on correct tick removal were produced and published on the Autonomous Community and the Ministry of Health websites as a means of reaching the general population. They were also sent by email to health workers at hospitals and primary health centres. This was done in September 2016 and again as a reminder in the spring of 2017 as the new tick season approached. The messaging stressed the importance of removing ticks with tweezers (not alcohol, finger nails, or by burning them); and that if a tick was particularly difficult to remove, people should go to their primary health centre.
- Messages for preventing tick-associated risks. The Ministry of Health, in collaboration with the National Federation of Municipalities and Provinces (FEMP), coordinated an information seminar on the prevention of tick- and *Aedes albopictus*-associated risks, aimed at professionals working at municipality level who are responsible for sanitation and vector control.

At community level, people have reportedly not been very worried since the CCHF cases, but due to the increase in information concerning tick-borne diseases, we were informed that there has been an increase in the number of people in Castilla y León Autonomous Community going to their primary care centre doctors to have ticks removed.

## 4.3 Other observations

### Future information provision to the community at risk of tick bites

The community at risk of tick bites is heterogeneous and has a wide range of information needs. Our focus group discussion participants in Castilla y León Autonomous Community collectively recognised that (a) people need to know that there is a threat of tick-borne diseases in their area, but also that (b) those who are potentially at risk then have an obligation, once they are aware of this threat, to inform themselves so that they can ensure they are properly protected. Therefore, in a practical sense the authorities need to raise general awareness of the issue, and then ensure that detailed information is easily accessible when and where necessary. Community health centres and schools were identified as examples of useful venues for raising awareness on protective measures, with the potential for acting as ‘multipliers’ of information dissemination, to a wide population. This would help to minimise potential panic during a public health threat, as would apathy regarding the source and the risk – both of which would obviously have clear benefits for prevention.

As a group that requires legal authorisation, hunters are well organised and can be quite easily reached with information about tick-borne diseases through their various federations and clubs. For example, hunting schools provide information on how to take care of hunting dogs, including ticks and tick removal, and they also reported having social media groups through which they keep themselves well informed and connected. Hunters are also in quite regular contact with the authorities when, for example, they find sick animals while out hunting. They then call a vet who is supposed to come and investigate. There were, however, some frustrations voiced about the fact that this process is not always as efficient as it might be, indicating problems in the flow of information within the veterinarian network.

Similarly, farmers are in principle easily reached via the veterinarians with whom they work on a routine basis, so the theoretical possibility exists to inform them through this channel. However, while information meetings were regularly held for farmers in Castilla y León Autonomous Community by veterinarians prior to the 2008 economic crisis, financial limitations have brought these meetings to an end. Thus, a potential channel for providing farmers with information on prevention of tick-borne diseases is no longer being utilised.

Hikers are the least organised and most varied of the different interest groups with whom we spoke. Some organised hikers’ groups do exist, meeting up once a month or so, and these could theoretically be identified and targeted with information. However, most people go hiking into tick-infested areas alone without any sort of organisation. The suggestion was therefore made to take advantage of the information boards that are often to be found at car parks at the start of hiking routes by posting signs with messages about ticks and the prevention of disease. Links to websites run by the Autonomous Community public health authorities could also be included there, with QR codes that can be scanned by a mobile phone app to take the hiker directly to the site. In addition, the websites, which show hiking routes and are used by hikers for planning purposes, could be used for disseminating prevention information.

We understood that most of the immigrants in Castilla y León Autonomous Community speak enough Spanish to understand basic health messages, but that some may only speak Arabic. We were told that language issues would be taken into account in any campaigns to raise awareness of tick-borne diseases.

## Multi-sectoral simulation exercises

It was accepted that a degree of uncertainty at the start of a crisis is almost inevitable, and that established protocols may not always be followed perfectly. For example, during the first critical hours after the CCHF diagnosis had been made, there were bottlenecks in the exchange of information at the various administrative and technical levels. Consequently, journalists were aware of the situation before some of the key technical experts, who spoke of not being able to act because, as they saw it, key information was being withheld from them.

These experiences led to several calls from our participants to conduct multi-sectoral simulation exercises, including both national and Autonomous Community-level authorities, as a means of minimising errors during this critical phase. Simulations have previously been conducted on Ebola-type scenarios in healthcare settings, but these have not included other essential sectors such as communications. They have also focused on imported, not autochthonous cases – though after the CCHF experience, the latter should clearly also be included. It was not immediately clear if or how the community, which includes such a range of diverse groups, would or could be engaged in simulation exercises addressing infectious disease threats.

## Diagnosing the index case

The delay in diagnosing the index case has already been described above, but it may be important to highlight once again the importance of ensuring early diagnosis of any serious infectious disease. In this case, there was only one secondary case – who fortunately survived – but concerns were nonetheless raised by some of our interviewees that a more infectious pathogen could emerge in the future, with the potential to infect many more people before it is properly diagnosed and effective control measures are put in place.

There will, by definition, always be challenges in preparing for future, unknown threats, but this case underlines the importance of preparing not only for a recurrence of previous events – or, in military terms, fighting the last battle – but also for anticipating the next, unknown one. For example, while dengue and Zika have ensured that a great deal of effort in Spain is now focused on preparedness for these and other emerging mosquito-borne diseases (e.g. West Nile Fever), until 2016 ticks were low priority for public health authorities.

With the CCHF experience in mind, our interviewees indicated a shift in thinking from ‘it can’t happen here’ to ‘we need to be ready in case it does happen here’. We were advised that this thinking needs to be extended specifically to triage nurses in hospitals and to nurses in primary care settings, who should receive additional training on the identification of unexpected and potentially dangerous infectious diseases. Ultimately, what is needed is a more sensitive and specific public health system, so that serious problems are quickly picked up and while false alerts, that can bring about public panic and considerable expense to the health system, are minimised.

## Rural-urban divide in perceptions about tick-borne disease

The community respondents in Ávila overwhelmingly perceived people from the cities to be more concerned about tick-borne diseases than they are, even though those in the rural areas are actually most at risk. This applies to CCHF as well as to other tick-borne diseases. For them, ticks are a regular part of life, and they have extensive experience of being bitten, as well as good knowledge of preventive practices. This has implications for any communication strategy to prevent tick-borne diseases. One size will not necessarily fit all: rural and urban populations should be targeted with different messages.

## 5. Good practices and conclusions

### 5.1 Good practices

This section outlines a set of 13 good practices for promoting collaboration and synergy between the authorities and the community identified in this study, as well as four other key lessons learned. These all apply specifically to CCHF, but also to other zoonoses or to public health threats more generally. For this reason, we have identified each of the good practices as being specific to tick-borne diseases (T), other zoonoses (Z), and/or to public health threats more generally (PH).

The good practices include both points that have already been implemented by the authorities in Spain to a greater or lesser extent and areas where we were told that improvements could still be made. As such, the good practices and lessons learned are presented as objectives that may be worked towards, both by the authorities in Spain and by those in other EU Member States. Note that each of the points below was suggested to us by one or more of our informants.

An overall observation from our week in Spain and from the reviewed documentation was that within institutional settings, existing protocols provided a clear basis for communications and collaboration and, apart from the specific challenges identified above, these channels reportedly worked well. Much less focus has previously been given to promoting collaboration and synergy with the community, however, hence the emphasis given to these below.

#### Promoting inter-sectoral collaboration and synergies between the authorities

- Implement a multi-sectoral tick surveillance programme, with activities integrated between the Ministry of Health and the Ministry of Agriculture (T, Z). A 'One-Health', multi-sectoral approach to tick surveillance – including the Ministry of Health, the Ministry of Agriculture, and environmental health partners – offers the possibility for quickly responding to an outbreak, identifying at-risk geographical areas, and providing enhanced messaging on prevention and control for those at-risk. ECDC can offer to provide scientific expert advice, for example via the Vectornet tick-borne disease group, on tick behaviour, risks linked to tick-bites, and surveillance data interpretation.
- Conduct multi-sectoral simulation exercises, including key stakeholders at national, Autonomous-Community and local levels (PH). Multi-sectoral simulation exercises, including both national and regional level authorities as well as relevant ministries (e.g. Agriculture and Environment) have the potential for identifying bottlenecks and gaps in preparedness and response protocols that can then be addressed. Efforts to conduct such exercises could include autochthonous cases of disease. ECDC may be able to organise a simulation exercise in Spain, perhaps in coordination with one of the neighbouring EU countries (i.e. Portugal and/or France).

#### Promoting collaboration and synergy within the health sector

- Develop a protocol, in advance of any public health incident to establish a crisis committee and identify a spokesperson to represent the authorities (PH). By making provisional agreements before the event with key institutional and individual actors who may be required to join a crisis committee or to act as spokespeople, the response to a public health incident can be properly coordinated during the first few critical hours. This can significantly reduce the possibility of errors at the start that may slow up or otherwise hinder subsequent response activities.
- Ensure efficient and smooth information exchange within and between key health sector institutions, including public health agencies at both national and Autonomous-Community level, healthcare facilities, and laboratories (PH). It should always be a priority to ensure that operational personnel and technical experts receive all the relevant information that may be available as soon as it is obtained and validated.

#### Promoting collaboration and synergy between the authorities and the community

- Adopt different approaches, as appropriate, when following up different categories of potentially exposed contacts in the community (PH). Health workers who may be exposed to nosocomial infection of a zoonotic agent can be followed up through professional channels; but people exposed by other means, such as via a vector, will probably not be directly connected to the health sector, and they will need to be identified and followed up using alternative means. Contact follow-up protocols need to be sufficiently flexible to take these different contact categories into account. ECDC may be able to make available to Member States a generic contact tracing mobile app, based on those developed for Ebola in West Africa.

- Use pre-existing connections with the community and local organisations for the effective dissemination of information to people who may be at risk of tick-borne or other zoonotic diseases (T, Z). Hunters in Spain are in close contact with one another and the authorities (during the licencing process, and when they find and report sick animals); while livestock farmers are regularly in touch with veterinarians. These channels can be used to facilitate the effective provision of prevention information to people who are potentially at risk of infection.
- Provide feedback to community members who contribute to surveillance and other preparedness activities by collecting and sending in ticks (T, Z): People will generally be more cooperative with the 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 datasets to which they are contributing. This could take the form of annual summaries showing the geographical patterns of tick infestation, or similar.
- Ensure that systematic efforts are made to monitor community perceptions of any public health incident (PH). By monitoring community perceptions of an issue, it will be possible for the authorities to respond to any misinformation or rumours that may emerge. Such a 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 topics of concern that are raised on telephone hotlines.
- Recognise the rural-urban divide in perceptions about tick-borne diseases when designing communication strategies and targeting messages (T, Z, PH). Ticks are seen as a greater problem by those living in the city, who are at negligible risk, than by those in the rural areas who are affected by them on a daily basis – this has implications for any communication strategy. Rural and urban populations should be targeted with different messages, possibly disseminated via different channels.
- Ensure that risk communication messages reach people who could be considered vulnerable to infection, but who may not easily receive or access information on prevention. This could include people who do not speak Spanish and who may therefore need translated materials (PH). The linguistic needs of tourists, temporary visitors and non-Spanish speaking immigrants – especially those who work with livestock, and who may therefore be at increased risk from ticks or other zoonotic diseases – should be taken into account in any communication campaigns.
- Use occupational health specialists as a valuable resource for disseminating information on prevention to specific, at-risk professions (PH). In addition to information dissemination, these occupational health experts can also play a key role in supporting contact tracing and follow up activities.
- Build trusting relationships with journalists prior to the crisis (PH). Relationships with journalists can work in two directions: they can act as important sources of information about happenings 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 bring about significant mutual benefits.
- 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 (Z, PH). An informed, at-risk community understands the challenges to adopting effective preventive practices for themselves better than anyone. Through dialogue with well-placed community representatives, it may be possible to identify areas where improvements can be made to prevention that can then be disseminated either to the wider population or to specific risk groups, as appropriate.

## Other important lessons learned

- Introduce evaluation activities into Standard Operating Procedures, and establish the practice of sharing experience and lessons learned among stakeholders in different sectors and at different levels (PH): Efforts to conduct formal evaluations after a public health incident can ensure that institutional memories are sustained and that lessons learned are remembered over the longer term. Relevant authorities could be encouraged to institutionalise regular post-event evaluations by including them as a requirement within SOPs. ECDC may be able to support colleagues at national level (and, with their agreement, at local level) by providing them with evaluation tools, and by organising meetings to discuss lessons learned that can be applied for further improvements in preparedness planning.
- Check that haemorrhagic fever protocols have been updated since the 2014-15 Ebola crisis (PH). Following on from the previous point, a wealth of experience was gained during the Ebola crisis, and it is important to ensure that the key lessons learned are captured by updating the relevant protocols. This can have benefits for the control of viral haemorrhagic fevers as well as for other serious infectious diseases.
- Establish tracking systems for biological samples in reference laboratories (PH). It is important to know who has handled specific biological samples during processing, so that individuals who may have been exposed to dangerous pathogens can be identified and placed under surveillance, as appropriate.
- Train triage and primary care nurses to be on the lookout for unexpected and potentially dangerous infectious diseases, for the purposes of rapid diagnosis and initiation of appropriate public health measures (PH). As the first potential point of contact with the healthcare system for a patient with a serious infectious disease, triage and primary care nurses have a critical role to play in the early identification and diagnosis of any emerging disease, and thereby the triggering of the process that leads to rapid isolation of the patient and appropriate use of PPE for health workers.



## 5.2 Study strengths and limitations

This study benefited from the wide range of professional backgrounds represented by the interviewees and focus group participants, and from the inclusion of stakeholders at national, Autonomous Community and community level. Furthermore, our semi-structured qualitative interview and focus group discussion methodology encouraged people to speak about issues in a way that *they* wanted to talk about them, and to raise topics that *they* felt were important. Although it was a relatively small project (just 28 people), we believe that we were able to identify and explore most, if not all of the core points relating to preparedness for and response to the 2016 CCHF events in Spain.

The fact that we were accompanied to all the interviews and focus group discussions by CCAES staff meant that we could discuss with them over the course of the week's visit what we were learning, and also ask questions to clarify issues which was of great assistance to us. Their presence also allowed them to meet and listen to stakeholders from the Autonomous Community and other community levels who they may not otherwise have encountered, providing them with an additional and valuable perspective of events.

However, it is possible that the presence of CCAES 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 level officials. If this was the case, we do not believe that it caused any significant biases in the database, as most issues were discussed with more than one respondent, and while there was not universal agreement on everything, our study participants generally complemented one another's content rather than contradicting it.

## 5.3 Conclusions and possible directions for future research

This study has demonstrated the potentially substantial value to be gained by building collaboration between health and non-health sector authorities and the community in the prevention and control of zoonotic and other communicable disease threats in Spain. Goodwill and a willingness to work together was apparent from all the stakeholders interviewed, but any successful long-term collaboration will require significant ongoing efforts, planning, and resources.

Consideration could be given to directing future operational research to focus on how best to implement and sustain the good practices identified above, and to develop additional means of bringing about effective community-authority collaborations 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 as well as EU Decision 1082.

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# Annex 1. Documents collected during country visit

The titles/headings of all the documents cited below have been translated from Spanish into English.

## National level (Ministry of Health, Social Services and Equality, CCAES)

- Confirmation of cases of Crimea-Congo haemorrhagic fever in Spain (Press release, 1 September 2016)
- Situation note on Crimea-Congo haemorrhagic fever (Press release, 3 September 2016)
- Questions and answers on the infection caused by the Crimea-Congo haemorrhagic fever virus (Information sheet, 17 May 2017)
- CCHFV study on ticks, September 2016–April 2017 (Map of affected areas in Castilla y León AC)

## Madrid Autonomous Community

- Health [Ministry] confirms cases of Crimea-Congo Haemorrhagic Fever (Press release, 1 September 2016)
- Action guide against tick bites (advice for medical staff, including algorithm for suspected cases, October 2017)
- Ticks: discomfort and diseases that they transmit (Chapter in information booklet, also including a chapter on the use of insect repellents, March 2017)
- Situation update on the evaluation of transmission risk for Crimea-Congo haemorrhagic fever virus (April 2017)
- Epidemiological surveillance network of Madrid Autonomous Community: surveillance protocol for Crimea-Congo haemorrhagic fever (Official protocol, 16 June 2017)
- Recommendations for the prevention of diseases from tick bites (four-page infographic leaflet, no date, but produced after the CCHF event)
- Stakeholder connections at the Environmental Health Unit (no date).

## Castilla y León Autonomous Community

- The authorities consider the risk of Crimea-Congo haemorrhagic fever to be very low (Press release, 1 September 2016)
- The authorities maintain follow-up of six people for Crimea-Congo fever [sic] (Press release, 5 September 2016)
- Prevention of tick-borne diseases (two-page infographic leaflet, no date)
- How to remove a tick (two-page information sheet, no date)
- Prevention of infections transmitted by ticks (two-page information sheet, no date)
- Information for health professionals regarding characterisation of Crimea-Congo haemorrhagic fever in suspected cases (four-page information sheet, no date)
- Evaluation algorithm for investigation of Crimea-Congo haemorrhagic fever for the epidemiological surveillance network of Castilla y León (two-page document with flow charts, no date).

## Community groups

- The ticks are coming! Advice for prevention (article in hunting magazine, *Cazawonke*, 16 May 2012)
- Goodbye to the ticks, fleas and other parasites that affect your dogs (article in hunting magazine, *El Coto de Caza*, 29 May 2013)
- Ten commandments for hunters and countryside lovers to protect against ticks (article printed from website of hunters, Real Federación Española de Caza, no date).

## Annex 2. Interview and focus group discussion questions

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.

### 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).
2. Could you map out on a piece of paper (a) the different stakeholder/interest groups or groups that have previously been involved with preparing for tick-borne diseases, and (b) those that were involved in responding to the 2016 CCHF cases. Which of these groups would you define as coming from the community, and which would you define as ‘administration’? Do you think there are any stakeholder/interest groups – institutional or from the community – who are missing from this map, but who *should* be included in order to ensure better preparedness and response in future?

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

##### *Anticipation phase (prior to the event)*

3. Has your institution produced any protocols, guidelines, or information leaflets for the population regarding the prevention of tick-borne diseases? [Obtain copies if possible]
4. To what extent were there any sort of public health preparedness activities 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?
5. [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 level respondents] In general, do you think that the community trusted the public health & scientific administration in Castilla y León and Madrid Autonomous Community prior to the event? [For all respondents] Had there been any specific events (such as other disease outbreaks) that promoted or undermined trust? Details.

##### *Response phase (during the event)*

6. [For national level respondents] Were there sufficient numbers of dedicated professional staff, able to respond to the case? [For autonomous community-level respondents] Were there sufficient numbers of dedicated professional staff in Castilla y León and Madrid Autonomous Community able to respond to the case? [For all respondents] Were there any problems, for example with funding, that may have limited the response?
7. 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?
8. 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?
9. 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?
10. 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?
11. 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?
12. Do you think there were any groups in the community who, for any reason, were excluded from the response? Details.

13. 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?

### *Recovery phase (after the event/outbreak)*

14. 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?
15. 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**

16. 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?
17. [Only for Autonomous Community-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?
18. 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?
19. Is there anything else you would like to add?

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

### **Part 1 - Mapping the different stakeholders**

1. Could you map out on a piece of paper (a) the different stakeholder/interest groups or groups that have previously been involved with preparing for tick-borne diseases, and (b) those that were involved in responding to the 2016 Crimean–Congo haemorrhagic fever (CCHF) cases. Which of these would you define as coming from the community, and which would you define as “Administration”? Do you think there are any stakeholder/interest groups – institutional or from the community – who are missing from this map, but 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)*

2. 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.
  - a) 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?
  - b) 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?
  - c) 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?
3. In general, do you think that the community, and in particular your own interest group, trusted the public health & scientific administration in Castilla y León/Madrid 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)*

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

5. 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?
6. 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?
7. To what extent did different interest groups cooperate with each other during the response to this event? Examples?
8. 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.
9. 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?

### *Recovery phase (after the event/outbreak)*

10. 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?
11. 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 3 - Overview**

12. 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?
13. 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?
14. 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?
15. Is there anything else you would like to add?

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