Community engagement and institutional collaboration during outbreaks of Shiga toxin/verocytotoxin-producing *Escherichia coli* in Ireland

Country visit report

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This report was commissioned by the European Centre for Disease Prevention and Control (ECDC), coordinated by Judit Takács, and produced by Umeå University, Sweden.

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Community engagement during Shiga toxin/verocytotoxin-producing *E.coli* outbreak in Ireland

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## Abbreviations

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<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>CIDR</td>
<td>Communicable Infectious Disease Reporting System</td>
</tr>
<tr>
<td>ECDC</td>
<td>European Centre for Disease Prevention and Control</td>
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<tr>
<td>ECI</td>
<td>Early Childhood Ireland</td>
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<td><em>E. coli</em></td>
<td><em>Escherichia coli</em></td>
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<tr>
<td>EPA</td>
<td>Environmental Protection Agency (Ireland)</td>
</tr>
<tr>
<td>EPIS</td>
<td>Epidemic Intelligence Information System</td>
</tr>
<tr>
<td>EWRS</td>
<td>Early Warning and Response System</td>
</tr>
<tr>
<td>HPSC</td>
<td>Health Protection Surveillance Centre</td>
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<tr>
<td>HUS</td>
<td>Haemolytic Uraemic Syndrome</td>
</tr>
<tr>
<td>HSE</td>
<td>Health Service Executive</td>
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<tr>
<td>IHR</td>
<td>International Health Regulations</td>
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<tr>
<td>NFP</td>
<td>National Focal Point</td>
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<tr>
<td>NRL</td>
<td>National Reference Laboratory</td>
</tr>
<tr>
<td>OCT</td>
<td>Outbreak Control Team</td>
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<tr>
<td>PCR</td>
<td>Polymerase Chain Reaction</td>
</tr>
<tr>
<td>STEC/VTEC</td>
<td>Shiga toxin/verocytotoxin-producing <em>Escherichia coli</em></td>
</tr>
<tr>
<td>SOP</td>
<td>Standard Operating Procedure</td>
</tr>
<tr>
<td>TUSLA</td>
<td>Child and Family Agency</td>
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<tr>
<td>WGS</td>
<td>Whole Genome Sequencing</td>
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</table>
Executive summary

Background

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

As part of this wider project, we present here the findings of a case study into outbreaks of Shiga toxin/verocytotoxin-producing Escherichia coli (STEC/VTEC) at childcare facilities in Ireland, conducted in November 2018.

Enterohaemorrhagic E. coli infections are quite common in humans, typically causing gastroenteritis with bloody diarrhoea. STEC/VTEC is fundamentally a zoonosis as it is mainly acquired by contact with animals and/or their faeces and by consuming contaminated food or water. Across the EU 6 647 cases of STEC/VTEC were reported in 2017, 37% of which were hospitalised due to haemolytic-uraemic syndrome (HUS), with 20 deaths. In 2017, Ireland had the highest notification rate of confirmed STEC/VTEC cases in the EU (16.6/100 000 population) [1].

Aim

The aim of this case study is to identify enablers and barriers for community and institutional synergies related to preparedness and control of STEC/VTEC outbreaks in childcare facilities in Ireland. Specifically, the study aims to:

- identify good practices and patterns of cooperation between affected communities and the official institutions mandated to address STEC/VTEC outbreaks;
- identify inter-sectoral collaboration between health and non-health-related sectors with regard to infectious disease outbreaks, such as STEC/VTEC;
- identify model community engagement actions for other EU countries.

Methods

A qualitative case study research design was adopted, including the following methodologies:

- documentary review;
- interviews with technical experts working at national and community level, and with representatives of an STEC/VTEC-affected community (n=15);
- focus group discussions with technical experts and community representatives (n=25);
- stakeholder mapping.

Fieldwork was conducted during a visit to Ireland during the period 26–30 November 2018, followed up by phone interviews the week after with people we had been unable to talk to when in the country. We sought information about community engagement during STEC/VTEC outbreaks in general, but also in relation to a specific outbreak in a childcare facility, or crèche, that took place earlier in 2018. The data were subjected to thematic analysis in NVivo qualitative software and UCINET social network software. The analytical framework of the preparedness cycle (pre-incident, incident and post-incident phases) was used to organise the findings.

Findings

Stakeholder mapping

The stakeholder mapping indicated that institutional stakeholders dominate the response, with the community having a significantly smaller role to play than that of the authorities.

Pre-incident phase

The pre-incident issues generally referred to contextual, background factors that could affect the way an STEC/VTEC outbreak emerges, and that may also frame different aspects of the response. These included:

- strong collaboration between all the main health sector stakeholders with regard to STEC/VTEC, and ongoing support for crèches from Early Childhood Ireland (a civil society organisation that develops awareness-raising materials on, for example, hand hygiene);
- close cross-border relationships with public health counterparts in the UK, and especially in Northern Ireland;
- uneven coverage of infection control inspections in crèches.
Incident phase

- Strong community collaboration facilitated preparation of the crèche for the deep cleaning that was required before re-opening could be authorised. This collaboration resulted mainly from the concerns of many parents about the financial implications of crèche closure for their families, since they would have to take time off work to care for their children – whether they were infected with STEC/VTEC or not – at home.
- The outbreak highlighted the challenges faced by both the regional Department of Public Health and the National Reference Laboratory. Respondents expressed the view that the Regional Department of Health was chronically under-resourced, and the National Reference Laboratory was under considerable pressure during this period, with numerous other STEC/VTEC outbreaks occurring in Ireland at the same time. Perceived delays in receiving results led to frustration among some parents.

Post-incident phase

- Post-outbreak training on infection prevention and control was provided by the regional Department of Public Health for staff when the crèche reopened.
- STEC/VTEC outbreak reports – in general, but also specifically in the case we investigated – focus primarily on epidemiological and clinical issues. Reference to community engagement activities, such as telephone communications with crèche staff and parents, face-to-face meetings with staff and parents, and the distribution by nurses of stool sample pots and associated information to staff and parents is not extensive.

Suggested good practices

A set of suggested good practices for promoting community engagement during STEC/VTEC outbreaks has been identified in this study. They are all based on points raised by our respondents and they include:

- **Inter-sectoral collaboration**: while collaboration between all the main health sector stakeholders was strong, additional measures to further improve such collaboration, including with regard to hygiene inspections in crèches, could be of benefit.
- **Documentation**: systematic and comprehensive inclusion of reference to community engagement activities in official STEC/VTEC outbreak reports would highlight the importance of this work, and create the opportunity for a fuller focus on these activities. In addition, production by a suitable organisation of evidence-based, written guidance for crèche owners whose facilities have been closed because of STEC/VTEC may also promote adherence to the necessary public health practices.
- **Finances and logistics for parents**: the challenges faced by parents of children with extended STEC/VTEC infection need to be addressed.
- **Health literacy and training**: knowledge of STEC/VTEC prevention and control needs to be enhanced, for the wider community, for health workers, and for crèche owners and staff.
- **Communication**: taking all the resource and logistical constraints into account, it would be beneficial if communication channels between public health authorities and crèche owners could be streamlined, to the extent possible during an outbreak.
Introduction and context

Background

Public health emergency preparedness (PHEP) refers to ‘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’ [2]. Since the 2014–2016 West African Ebola outbreak, the potential role of communities in PHEP has been increasingly recognised, as has the fact that communities can be seen as resources that may be effectively used by the authorities during public health emergencies [3]. ‘Community’ here refers to populations that are directly affected by, or that may be at risk from the disease in question. Thus, the community is seen as distinct from the government authorities who are tasked with preparing for and responding to the disease.

In order for community-oriented PHEP efforts to be successful, it is necessary to understand how and the extent to which institutions in the health and relevant non-health sectors can collaborate with the community, as well as to identify good practices that have worked in one setting and by extension, may be applied to others. This approach reflects the call by the 2015 Sendai Framework for Disaster Risk Reduction for a broader, more people-centred preventive approach through engagement with all relevant stakeholders [4]. Similarly, EU Decision 1082/2013/EU on serious cross-border threats to health emphasises the need for public sectors to work together more closely and to create opportunities for collaboration within the context of PHEP [5].

A critical starting point for any successful community preparedness activity is that it should be based on mutual trust and respect between the various institutional and community-based actors. This involves bringing together a wide range of organisations and people and nurturing collaborative relationships between them. However, achieving this goal is invariably a complex undertaking in any setting [6].

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 address a given health threat; and by extension, may be applied to others. This approach reflects the call by the 2015 Sendai Framework for Disaster Risk Reduction for a broader, more people-centred preventive approach through engagement with all relevant stakeholders [4]. Similarly, EU Decision 1082/2013/EU on serious cross-border threats to health emphasises the need for public sectors to work together more closely and to create opportunities for collaboration within the context of PHEP [5].

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Study aims

The main aim of all four of the case studies is to collect evidence and share good practices related to inter-sectoral collaboration and community preparedness for public health emergencies, by examining what has worked in different contexts. The work also aims to support the implementation of EU Decision 1082/2013/EU on serious cross-border health threats.

Specifically, the studies aim to:

• identify what has worked and not worked in different contexts, with particular attention paid to practices and patterns of cooperation between affected communities and the official institutions mandated to address a given health threat;
• identify and analyse inter-sectoral collaboration as well as community-institutional synergies, and to provide examples of collaborative efforts between health and non-health-related sectors;
• produce guidance for EU/EEA Member States on community engagement for public health emergency preparedness based on all four case studies mentioned above (i.e. Spain [7, 8] the Netherlands [8, 9], Iceland, and Ireland) as well as a literature review (which preceded this work) [10].

It is hoped that the four case studies will directly benefit the participating countries by raising awareness among important stakeholders of the need for inter-sectoral collaboration and the development of community-institutional synergies; by providing a situation analysis of their preparedness status for specific diseases and indicating areas that may need additional attention, and by identifying good practices in order to provide the means for strengthening inter-sectoral and community-institutional collaboration. The guidelines produced as a result of the work will be shared among other EU Member States, who will therefore also benefit from this process.
The Irish public health system for outbreak response

The Health Service Executive (HSE) is a large organisation of over 100 000 employees, mandated with the task of running all of the health services in Ireland [11]. Public health is an important component of HSE's work.

The country has eight public health regions, each of which is led by a Medical Officer of Health, who has responsibility for the coordination of regional or local-level outbreak responses. To this end, Medical Officers of Health have considerable legal authority under the Infectious Diseases Regulations, 1981. These Regulations state that: ‘On becoming aware, whether from a notification or intimation under these Regulations or otherwise, of a case or a suspected case of an infectious disease or of a probable source of infection with such disease, a Medical Officer of Health, or a health officer on the advice of a Medical Officer of Health, shall [emphasis in the original] make such enquiries and take such steps as are necessary or desirable

- For investigating the nature and source of such infection,
- For preventing the spread of such infection,
- And for removing conditions favourable to such infection.’ [12]

National-level outbreak responses or those with an international element are led by the National Medical Officer of Health (also known as the Assistant National Director for Health Protection), with the assistance of the Health Protection Surveillance Centre (HPSC). HPSC is a specialist centre for the surveillance of communicable diseases, and it works to ‘protect and improve the health of the Irish population by providing timely information and independent advice, and by carrying out disease surveillance, epidemiological investigation and related research and training’ [13].

When an outbreak is declared, various stakeholders are invited to join in the response. Different stakeholders would participate in different sorts of outbreak. For example, in the event of STEC/VTEC at a crèche1, the following agencies (all of which are a part of HSE) may be involved:

- Department of Public Health
- National Reference Laboratory-STEC/VTEC, Public Health Laboratory, at Cherry Orchard Hospital, Dublin.
- Health Protection Surveillance Centre (HPSC)
- HSE Communications (depending on the size and nature of the outbreak)
- Environmental Health Service - national and regional teams
- Clinical microbiology from local/regional hospital
- General practitioners.

The Department of Agriculture does not generally become involved during routine crèche-associated outbreaks of STEC/VTEC disease.

STEC/VTEC in Ireland

Shiga toxin/verocytotoxin-producing *Escherichia coli* (STEC/VTEC) are gastro-intestinal bacteria that cause a highly infectious diarrhoea, which may be bloody. Up to 15% of cases, especially in children under 10 years of age, may go on to cause serious systemic illness in the form of haemolytic uraemic syndrome (HUS). Across the EU, 6 647 cases of STEC/VTEC were reported in 2017, 37% of which were hospitalised due to HUS, with 20 deaths (case fatality rate = 0.5%) [1]. STEC/VTEC and HUS are both urgently notifiable conditions in Ireland: treating physicians need to notify public health authorities within 24 hours of case diagnosis. In 2017, Ireland had the highest annual notification rate of STEC/VTEC in the EU (~16.6/100 000 population) [1].

STEC/VTEC lives as a commensal, usually without any ill effect, in ruminants, including cattle and sheep. These animals provide the primary reservoir for human infection. The bacteria are transmitted through ingestion of food or water that has been contaminated by infected faeces. In Ireland, a review of outbreaks between 2004 and 2012 found that person-to-person spread accounts for 56% of cases (many of which occur in crèches), waterborne transmission for 25%, foodborne for 10%, and animal contact/environmental exposure for 9% [14]. There was a large excess of STEC/VTEC cases in the summer of 2018, with 91 cases linked to what was believed to be a single foodborne outbreak [HPSC, personal communication].

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1 In Ireland, the term 'crèche' refers to a childcare facility that cares for children up to the age of around 5–6 years.
The incidence of STEC/VTEC has increased substantially in Ireland in recent years (see Figure 1), with 839 cases notified in 2016 [15]. There have been several reasons for this:

- **Improved diagnostics**: the widespread introduction of Polymerase Chain Reaction (PCR) screening in regional or primary referral hospitals picks up many STEC/VTEC cases that would have been missed when using the older, serology-based diagnostic culture methods. In addition, further recent advances such as Whole Genome Sequencing (WGS) have facilitated the detailed epidemiological analysis of STEC/VTEC outbreaks.

- **Private water supplies**: the use of private water supplies by around 20% of the Irish population [16], which may be vulnerable to contamination by agricultural slurry, is a major factor contributing to the spread of STEC/VTEC in Ireland. This point is discussed further below (see Section 6 under ‘Pre-incident phase’).

- **Crèches**: Ireland has undergone massive social change over the past two decades, with women increasingly entering the workforce and a consequent need for rapid increases in the country’s childcare capacity. The fact that young children are being cared for in a group setting increases the risk and conditions favourable to the spread of VTEC. Detailed guidelines have been produced by HPSC for the prevention of infectious disease in childcare facilities, specifically for handwashing, nappy hygiene, and potty/toilet management [17], as well as for handling an outbreak of diarrhoea and vomiting [18].

Closing a crèche because of an STEC/VTEC outbreak – which is standard practice – can have serious financial consequences, both for the crèche business itself but also for the parents, who are often then obliged to take time off work to care for their children until clearance for re-opening is provided. This issue lies at the core of the work presented in this report.

### Definitions

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

- ‘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’ [19].

- ‘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’ [2].

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2 There are 222 full daycare settings registered with Tusla (Child and Family Agency) which cater for over 100 children
Study methodology

Study design and participants

A qualitative case study approach was taken in this project [20], based on four data sources: (a) documents; (b) interviews with a range of technical experts, and community members who have been affected by STEC/VTEC; (c) focus group discussions with technical experts and community representatives and (d) stakeholder mapping. Details of each of these data sources are given below. The research team collected most of the data in Ireland during the week of 26–30 November 2018. Additional interviews were conducted by telephone during the first week of December 2018 with some community respondents who we had been unable to meet when in the country.

Several potential respondent categories were initially identified by the research team at the national, regional and community levels, and discussed with the Irish National Focal Point (NFP) for Preparedness and Response, and ECDC. We collectively agreed upon these respondent categories, as presented in Table 1. Those we ended up speaking with are set out in Annex 1.

Table 1. Proposed respondent categories for the study

<table>
<thead>
<tr>
<th>Institutional stakeholders at national level</th>
<th>Institutional stakeholders at regional level</th>
<th>Affected communities</th>
</tr>
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<tbody>
<tr>
<td>Department of Public Health</td>
<td>Local public health authorities</td>
<td>Staff and owner of childcare facilities</td>
</tr>
<tr>
<td>National Reference Laboratory – STEC/VTEC</td>
<td>Primary health care</td>
<td>Parents</td>
</tr>
<tr>
<td>Hospitals</td>
<td>Education sector</td>
<td></td>
</tr>
<tr>
<td>Surveillance system</td>
<td>Food supply/control</td>
<td></td>
</tr>
<tr>
<td>Environmental health</td>
<td>Water supplies</td>
<td></td>
</tr>
<tr>
<td>Occupational health</td>
<td>Agriculture</td>
<td></td>
</tr>
<tr>
<td>Education sector</td>
<td>Environmental health</td>
<td></td>
</tr>
<tr>
<td>Agriculture sector</td>
<td>Occupational health</td>
<td></td>
</tr>
<tr>
<td>Food supply/control</td>
<td>Local media</td>
<td></td>
</tr>
<tr>
<td>Water supplies</td>
<td></td>
<td></td>
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<tr>
<td>Media</td>
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</table>

Most study participants were recruited by the Irish NFP who also organised the agenda for the one-week country visit (see Annex 1 for the schedule). The four parents who we interviewed from the crèche volunteered to participate following an invitation to all parents sent out by the crèche owner. Most study participants were recruited by the Irish NFP who also organised the agenda for the one-week country visit (see Annex 1 for the schedule). The four parents who we interviewed from the crèche volunteered to participate following an invitation to all parents sent out by the crèche owner.3

Table 2 shows the numbers of participants in this study; details of their institutions and/or positions in the community are provided in Annex 1. Names or job titles are not provided in any cases in order to preserve anonymity. We conducted a total of 11 interview and three focus group discussion sessions, and we spoke with a total of 40 participants: 21 were institutionally based and 19 came from within the community. The community participants included the owner and 10 staff members of a recently STEC/VTEC-affected crèche, four parents from the crèche we visited, and four parents of children currently in other crèches who had not personally experienced an STEC/VTEC outbreak. Two of the institutional interviews included three people, but in all other cases the interviews involved just one respondent.

Table 2. Number of focus group and interview participants

<table>
<thead>
<tr>
<th></th>
<th>Focus groups (number of participants)</th>
<th>Interviews (number of participants)</th>
<th>Total number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>National level (institutional)</td>
<td>0</td>
<td>7 (11)</td>
<td>11</td>
</tr>
<tr>
<td>Regional level (institutional)</td>
<td>1 (10)</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>Community</td>
<td>2 (15)</td>
<td>4 (4)</td>
<td>19</td>
</tr>
<tr>
<td><strong>Total number of participants</strong></td>
<td><strong>25</strong></td>
<td><strong>15</strong></td>
<td><strong>40</strong></td>
</tr>
</tbody>
</table>

3 We acknowledge that the recruitment process for these individuals could have introduced some bias, since they were by definition people with potentially strong opinions that they wanted to share with us.
Research team
The core research team consisted of a senior medical anthropologist from Umeå University, Sweden, who led the interviews, supported by a Dutch medical anthropology postdoctoral researcher who took notes and supported the analysis. Three ECDC experts in public health preparedness and outbreak response joined the core team for the first two days of the country visit. The Irish NFP and one colleague also joined several of the interview and focus group sessions. This provided the opportunity for clarification of some issues during the discussions and for reflection afterwards. It was not our impression that any of the respondents adapted their comments due to the presence of the NFP.

Data collection

Documents
A documentary review and analysis was conducted. The documents were provided by the Irish NFP and supplemented, where available, with material from the peer-reviewed literature. The documentary review sought to identify:

- policies concerning the prevention of acute gastroenteritis, including with regard to community engagement;
- reports concerning challenges faced in preventing, diagnosing (clinically and in the laboratory), and treating acute gastroenteritis;
- lessons learned from any simulation or training exercises on acute gastroenteritis that may have been held in the last five years (both national and international), as well as from actual cases and events in the two countries;
- documents on any recommendations regarding clinical and laboratory skills, interventions, or other capacities.

The product of the documentary review is presented above in the sections 'The Irish public health system for outbreak response' and 'STEC/VTEC in Ireland'. Note that all STEC/VTEC outbreak reports are confidential, internal documents, and we cannot therefore name or refer to them directly in this report.

Interviews and focus groups
An initial set of questions for the interviews and focus group discussions was derived from a literature review on community engagement that had previously been conducted for ECDC [10]. The questions were structured on the basis of a theoretical preparedness cycle that includes pre-incident, incident, and post-incident phases [21], and were adapted according to comments received from ECDC and the Irish counterparts. Within this theoretical preparedness cycle, the pre-incident phase involves preparation and planning; the incident phase involves management, monitoring, investigation and intervention and the post-incident phase involves recovery and identification of lessons learned. The final questionnaire is presented in Annex 2. In order to facilitate the interview and focus group discussion process, the questions were sent in advance (where possible) to the participants. Questions were designed to be broadly relevant to all interviewee categories, but the focus of the questioning varied, depending on the position and particular expertise and experience of each individual interviewee or focus group discussion informant.

After discussion and agreement about the possible respondent categories between the study team, ECDC, and the Irish NFP (as in Table 1), a detailed list of potential participants for interviews and focus groups was drawn up by the NFP. Each of these participants was then approached and invited to take part. Nearly all those who were approached were available and willing to be interviewed.

Most interviews were conducted at the Health Protection and Surveillance Centre (HPSC) offices in Dublin, but we also visited a recently STEC/VTEC-affected childcare facility, the Department of Public Health in an STEC/VTEC-affected region and, at national level, the Department of Agriculture, Food and the Marine. Four interviews were conducted with parents from the affected crèche by phone during the week after the country visit. Interviews and focus group discussions lasted between 45 and 120 minutes. Extensive notes were taken during interviews and focus groups which were cleaned and checked on the day of data collection. These notes provide the basis for the material presented below.

Stakeholder mapping
All interview and focus group participants (with the exception of those conducted by phone) were invited to contribute to our stakeholder mapping exercise. At the start of each interview and focus group, we requested the participants to draw out on a blank piece of paper all the different stakeholders and/or interest groups – both community-based and institutional – that they were aware of who had previously been engaged in an STEC/VTEC outbreak, either specifically in relation to the outbreak at the participating crèche, or more generally. In addition to
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identifying stakeholders who we may not previously have been aware of, this exercise also provided respondents with the opportunity to add points to the discussion that they felt were important, thereby providing an invaluable supplement to the pre-defined questions that we wanted to ask. Collectively, the exercise also offered us the opportunity to develop a snapshot overview of the whole STEC/VTEC community social network in Ireland [10].

**Ethical considerations**

We obtained written informed consent from all participants, except for the four parents interviewed by phone, who gave verbal informed consent. The consent form is set out in Annex 3. All interview and field note materials have been kept by the team leader and only the study team (which includes the ECDC staff involved) has access to it. Anonymity is guaranteed for all interviewees. We comply with Regulation (EC) No 45/2001 on the storage of personal data and ensuring citizens’ privacy. ECDC is the data controller of this processing operation, and the data was collected and stored by Umeå University on its behalf, in its role as processor of the data. All interview and documentary material was given to ECDC at the end of the study.

**Data analysis**

During qualitative analysis, 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 from the interviews, with additional codes included as they emerged inductively. Stakeholder maps were collected and their data compiled into UCINET software, with symmetry forced into the matrix.

The analysis sought to identify lessons learned, good practices, and outstanding gaps and challenges. Where appropriate, quotes have been included as illustrations of particular points made, and these are anonymised in order to protect the respective interviewees. The analysis placed the data into the context of the theoretical preparedness cycle described above, based on pre-incident, incident, and post-incident phases [21]. Where appropriate, we also distinguish between the cross-border, national and regional levels in the analysis.

The use of data from documents, interviews, focus group discussions, and stakeholder mapping permitted triangulation, a process that enables the validation of a set of findings through cross-verification from two or more sources. Triangulation about specific points was facilitated by asking more than one informant about each of the major issues of concern, thereby obtaining different perspectives.

A draft version of the report was sent to the Irish country team for comments and input. A validation exercise of this kind is an essential part of the case study analytical process.
Findings

An STEC/VTEC outbreak in a crèche

During the course of our visit to Ireland, we visited a crèche where there had been an STEC/VTEC outbreak in recent months\(^4\). The regional Outbreak Control Team (OCT) had become aware through the Communicable Infectious Disease Reporting System (CIDR) of a single case of STEC/VTEC in a child attending the crèche which meant that they had been alerted to the possibility of an outbreak. They informed the crèche and asked them to initiate an active surveillance process to ascertain whether there were any other cases in the facility. Advice letters were also sent to the crèche to share with all parents/caregivers about STEC/VTEC, with specific reference to bloody diarrhoea, what to do if their child fell ill, and a request to be vigilant.

Meanwhile, the crèche stayed open. The second STEC/VTEC case in a child attending the same crèche emerged a few days after the first, at which point an ongoing outbreak was declared. In accordance with national guidelines, the crèche was then immediately closed pending screening of all children and staff, with the requirement that two negative samples be collected around 24 hours apart before being eligible for readmittance. In addition, a site visit was conducted by the Department of Public Health, HSE officials, and the environmental health services. Finally, the premises were cleaned thoroughly (i.e. disinfection of all surfaces and objects, including toys and furniture).

A meeting for parents and staff was held at the crèche on the day of the closure, at which a public health consultant clarified what was known so far about the outbreak, the reasons for closing the crèche, and the importance of infection control measures to bring the outbreak to an end. Clinical nurse managers specialising in health protection and infection control were then deployed to the crèche to provide face-to-face information for parents and staff about the protocols for safely collecting stool samples, to distribute sample pots and to subsequently collect samples. The nurses were present for the first two weeks of the outbreak, and they were also available on the phone for advice, as necessary.

A great deal of time was spent by OCT members taking calls from the crèche owner and the parents asking about the results of stool samples, especially during the period when the crèche was closed and when their children were excluded from the crèche because they had not yet produced two negative samples.

As per protocol, an epidemiological investigation was conducted via questionnaire at the house of the index case and that of her grandparents (where she regularly stayed), in relation to their food consumption and water supplies. Water samples were taken from a well at the household on two occasions, and also at the grandparents’ home, but the results were STEC/VTEC-negative: the source of infection was never identified.

The conditions for reopening the affected crèche were all met within two weeks and children and staff were allowed to return once they had provided the two negative stool samples required. In total, there were fewer than 10 cases in this outbreak, none of whom developed HUS. One child remained STEC/VTEC-positive for nearly three months, and was therefore excluded from crèche for the full duration of this period.

Although we refer to this STEC/VTEC outbreak quite extensively below, no identifying characteristics are presented so as to ensure that the crèche and the affected community remain anonymous.

Stakeholder mapping

Figure 2 presents the product of the stakeholder mapping exercise, which is based on the discussions we had during data collection. As such, it constitutes the collective perspective of everyone we spoke to who was or may have been involved in the response to an STEC/VTEC outbreak in an Irish crèche.

The blue squares (towards the right side) represent institutional stakeholders, and the red squares (towards the left) represent community stakeholders. Those with larger squares have a greater role as ‘brokers’ of information and thereby as agents of outbreak control than those with smaller squares. Brokerage (‘betweenness’) measures indicate how much an actor (node) connects other actors who otherwise would not be connected. If brokers are removed, parts of the network would become disconnected.

Note that there are three separate squares for HPSC, one for the institution as a whole, a second for their Gastroenteric Zoonotic Vector-borne Disease Team, and a third for the Infection Protection and Control Team. Since all departments have their own particular roles and networks, it is important to specify the multiple tasks that they have.

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\(^4\) In order to maintain anonymity, we cannot give precise details regarding the time or setting of the outbreak.
The stakeholder map shows, first and foremost, that there is (or can be) a multiplicity of stakeholders engaged in STEC/VTEC outbreaks in Ireland, including those based at global, European, national, regional, and community levels. Institutional stakeholders dominate the picture, with the community appearing to have a significantly smaller role than that of the authorities. The major institutional stakeholders are the Health Surveillance Protection Centre in Dublin, including specifically its Gastro-Zoonotic and Vector-Borne Disease Unit and, to a lesser extent, the Infection Prevention and Control team; the National Reference Laboratory; and the Outbreak Control Team at regional level. The major community-based stakeholders are the affected crèche itself (i.e. the owner and staff) and the parents of children attending the crèche.

**Pre-incident phase**

The following issues are presented as existing pre-incident, or contextual issues that could affect the way an STEC/VTEC outbreak emerges, and that may also frame all aspects of response.

- Cross-border issues: as with all EU Member States, Ireland is connected to ECDC’s Early Warning and Response System (EWRS), and also to the Epidemic Intelligence Information System (EPIS), which is a platform used for the voluntary exchange of expert opinions. The country is of course also signatory to the WHO International Health Regulations [22]. Of these instruments, EPIS is the most frequently used in relation to STEC/VTEC, usually when an outbreak is deemed to be food-borne rather than water-borne, and hence when it may have implications for other EU Member States.

Since STEC/VTEC outbreaks in Ireland may emerge near the Northern Irish border, UK authorities may also be involved in the response – and vice versa, when an outbreak emerges near the border on the northern side. EWRS and IHR are reportedly never used in such cases, as cooperation is already so close. Public health professionals from both sides of the border have trained together, meet regularly at events in Dublin and Belfast and often participate in cross-border video conferences on matters of mutual concern. These informal but strong relationships are a great resource, although we were told that if they are not institutionally formalised, challenges may arise when a particular individual, or their designated replacement, is unavailable at a critical moment.

Formal cross-border collaboration also exists, such as the recently formed five-nations Public Health Microbiology Consortium, which includes Ireland, Northern Ireland, England, Scotland and Wales. This provides a means for the respective countries’ laboratories to work together, including on issues related to Whole Genome Sequencing (WGS) of different pathogens. Furthermore, respondents informed us that there have been occasions when, even though there is no service level agreement between the UK and Ireland, STEC/VTEC samples from Northern Ireland have been sent for analysis to the STEC/VTEC HSE National Reference Laboratory in Dublin, which in some cases can provide faster results than the equivalent laboratory in the UK.
Multi-sectoral issues: two major non-health sectors were discussed by our respondents in relation to STEC/VTEC: agriculture, and child protection and safety. Respondents indicated that milk and beef accounted for over 61% of the country’s agricultural output in 2017 [23], and it can therefore be seen as contentious if public health authorities make any definitive claims about cattle in a given area being responsible for an STEC/VTEC outbreak, because of the potential losses it could cause for the food industry.

Personal relationships between high-level stakeholders in agriculture and public health have historically not in favour of public health and it was not clear during our discussions how the acknowledged gaps in legislation regarding the prevention of cattle slurry entering water supplies could be addressed from a public health perspective. STEC/VTEC has a much lower infectious dose than many other gastro-enteric infections, and as such this dangerous disease is highly contagious.

Health sector collaboration: all the main health sector stakeholders reported strong collaboration before, during, and after an STEC/VTEC outbreak. These stakeholders included HPSC, the regional public health departments, the VTEC National Reference Laboratory at Cherry Orchard, and potentially affected general hospitals. Within the affected region that we visited, colleagues in the Public Health Department meet on a weekly basis to exchange information, while a national teleconference including all eight regional Medical Officers of Health is also held once a week to discuss developments on all matters of public health (i.e. not just STEC/VTEC). As indicated above in the section on cross-border collaboration, the relevant authorities from Northern Ireland may also take part if there is an ongoing cross-border outbreak.

Overall, this means that people know each other well, and, due to their long-standing relationships, they are well acquainted with their respective roles and responsibilities during an outbreak. However, while the system does generally work well, respondents indicated that limited human and financial resources at regional level require staff, including those working in the environmental health services and at the National Reference Laboratory, to provide a significant amount of ‘grace and favour’ work during outbreaks, and they are sometimes extremely stretched. That said, protocols for outbreak management that provide for adequate surge capacity are in place.

Previously, all eight regions in the country had their own questionnaire for collecting information about STEC/VTEC outbreaks, but efforts have now been made to standardise the data collection process through the development of a single, modular questionnaire that is used in all regions. This standardisation effort was acknowledged as having improved efficiency as well as saving time.

Scientific uncertainty about STEC/VTEC: the enforced closure of STEC/VTEC-affected crèches, and the exclusion from crèches of children with both STEC/VTEC-positive and STEC/VTEC-negative stool samples creates a heavy social and financial burden on affected communities. Current practice is necessary because of scientific uncertainty about several aspects of this potentially fatal disease, not least the fact that the same serotype strain can vary pathogenically. This greatly complicates health risk decision-making, making it necessary for the authorities to err on the side of caution in order to minimise the risk of a child becoming seriously ill or dying during an outbreak. Enhanced understanding of genetics, both at pathogen and human-host level, would facilitate a more targeted public health response to STEC/VTEC outbreaks in crèches, which in turn could significantly reduce the burden on the community:

- **Pathogen**: given that, under current guidelines, asymptomatic STEC/VTEC-positive cases should follow the same practice as symptomatic cases, and continue to be re-tested until they are negative, it would be important to know the risk of an asymptomatic, infected child – whether culture-positive or only VT1/VT2 PCR-positive – transmitting STEC/VTEC. This question of the pathogenicity of a given STEC/VTEC infection may be addressed by undertaking molecular typing of the isolates.
- **Human**: while many of the human risk factors that may determine whether an STEC/VTEC-infected individual goes on to develop serious illness, such as HUS, are well understood (e.g. age, general health status, immunosusceptibility, and the use of antibiotics in the acute phase of disease), there remain areas of human genetics and individual-level susceptibility which are not yet well understood, and may affect the disease outcome.

Research in several EU Member States has been underway on these topics for a number of years [25], with the ultimate objective of producing a decision-tree that may be used to predict the likelihood of severe disease in humans. In Ireland, we heard that there are resources within HPSC for conducting health services-related research, but STEC/VTEC has not recently been seen as a priority area, compared with issues such as uptake of HPV vaccine, for example.

Large numbers of private water supplies: almost 20% of the Irish population does not have access to public water supplies, especially in rural parts of the country [16]. Furthermore, legislation regarding the construction and maintenance of private wells is not always fully enforced, and since the water that such wells contain is predominantly surface water or run-off, agriculturally-contaminated water can quite easily find its way into sub-standard, un-inspected wells, potentially leading to human STEC/VTEC infection. Surveillance conducted by the Environmental Protection Agency (EPA) in 2017 found that 45% of 195...
groundwater monitoring sites across the country were contaminated with one or more *E. coli* bacteria (STEC/VTEC was not specified, but it would certainly have been included in the analysis) [26]. In addition, various stakeholders from HPSC have reported a widespread public perception that the water drawn from these wells is actually clean ‘spring’ water, which means that people may not feel the need to spend energy and money improving their wells under treatment to produce water of potable standards so that it tested for STEC/VTEC. In addition, water that tests clean one day can be contaminated by STEC/VTEC-containing slurry on the next day, so testing needs to be conducted on an ongoing and regular basis: the EPA recommends that all drinking water supplies should be monitored at least once a year for *E. coli*, with greater frequency required for some supply types [26]. We were told by HPSC that the government is taking this issue seriously, and that work is ongoing to expand the public supply system throughout the country.

- **The regional Outbreak Control Team:** unless an outbreak is particularly complex and large, the regional Department of Public Health that we visited generally includes the same people in their Outbreak Control Team (OCT), irrespective of whether an outbreak relates to STEC/VTEC or some other disease. Team members have disease specialisation during ‘peace time’, but during an event that requires surge capacity, as one of them told us, ‘everyone does everything’. They therefore know each other well, and they all understand their respective roles since they follow the national protocols for outbreak response. The team in the region generally includes a clinical microbiologist, environmental health officers (EHOs), surveillance scientists, health protection nurses, and a representative from the public health laboratory in the local hospital. The criteria for crèche closure are clear and unequivocal: if there are two epidemiologically connected cases in the same crèche, the crèche must be closed.

- **Official protocol for responding to STEC/VTEC outbreaks:** The regional Outbreak Control Teams are very experienced in dealing with STEC/VTEC outbreaks, and they follow a nationally defined protocol that outlines the main actions required [27]. These include when and how to conduct an initial epidemiological investigation with the parent or guardian of the index case, the epidemiological conditions that must be met in order to close a crèche, the multi-faceted criteria to be complied with before it can be re-opened, and the procedures for distributing and collecting stool sample pots.

- **Civil society support for crèches:** the great majority of crèches in Ireland are members of the civil society organisation Early Childhood Ireland (ECI), which represents their interests. ECI’s mission is ‘to inspire and enable members to provide quality experiences for young children and their families in their settings’ [28]. Currently ECI is working with the Food Safety Authority of Ireland on a hand-hygiene programme designed to give small children an understanding of how and when to wash their hands. The materials produced (leaflets and posters) are then physically delivered to crèches, and also posted on the ECI website to allow for wider access. When we spoke with a representative of ECI, they expressed keen interest in leading the development of a guidance document for STEC/VTEC-affected crèches and parents. The product would be more community-owned, and therefore better accepted, since it would be produced by a civil society group whose specific purpose is to represent and promote the interests of the crèches.

- **High potential impact of STEC/VTEC:** our HPSC respondents explained that the nature of STEC/VTEC is such that the vast majority of infected people will either be asymptomatic or suffer no more than a case of diarrhoea, but up to 10% can develop HUS, and (in Ireland, in spite of extensive clinical experience and consequently very good care) up to 1% of those patients may die [HPSC, personal communication]. In order to minimise this risk, an onerous set of control measures is required at community level. Crèche staff and the OCT reported that there can be considerable resistance to these control measures, especially if people’s pre-understanding of the disease is limited. This may be seen as a classic case of the public health conundrum, whereby the benefits of prevention are often invisible to the communities involved, and the actions taken to ensure prevention may be resented, resisted, or simply not taken seriously by the beneficiaries.

- **Crèche owners and staff:** good collaboration between the health authorities and the owners and staff of an affected crèche is essential for minimising any associated stress and anxiety in the affected community, as well as for controlling the outbreak. While most crèche owners and staff are extremely responsible and diligent in their care for the children, as well as their dealings with the parents, there are some exceptions. We heard from both national- and regional-level respondents of instances where parents were publicly blamed and shamed for their children being infected with STEC/VTEC, and where owners were hostile towards public health officials, actively obstructing control activities. (We emphasise that this did not happen at the crèche that we visited.) The regional public health authorities are, we were told, ‘hostages to fortune’ in this regard: response activities will always run more smoothly if they have a good collaboration with the crèche owners.
Various public health stakeholders mentioned another important contextual factor, concerning the very strict contracts that some crèche workers reportedly had (though we emphasise that this was not reported for the crèche that we visited). These workers have limited or non-existent employment benefits and therefore they cannot easily afford to stay away from work if they are sick themselves, even if they could be infectious for others. This clearly creates a health risk to the community, emphasising the fact that prevailing social and contractual conditions within some professions in Ireland can facilitate the initiation and/or spread of serious outbreaks.

- Community knowledge of STEC/VTEC: prior knowledge of STEC/VTEC was generally limited in the community we visited: as a staff member at the crèche explained: ‘No one knows what STEC/VTEC is, they think it has something to do with cars.’ The mother of one of the STEC/VTEC-infected children at the crèche told us of her fear when she received the diagnosis for her child: ‘I didn’t know what E. coli was, so I Googled it, and then, oh my God!’ However, she said that her concerns dissipated somewhat when her child continued to be in apparent good health. The parent of an uninfected child indicated that she herself had a reasonable knowledge of STEC/VTEC prior to the outbreak, but that ‘other parents didn’t know how serious it could be’. A possible reason for her own prior knowledge was the crèche’s proximity to another town where there had been an STEC/VTEC outbreak a few weeks earlier, where she had friends.

HPSC reported that staff at crèches do not have infection prevention and control as a mandatory part of their training, and as such, their knowledge about this essential issue may also be limited. Some training on the topic had been given by the regional Public Health Department two years previously to some of the staff at the crèche we visited, but this was a one-off, ad hoc event. HPSC has produced a standard document on common communicable diseases that can affect crèches [17], which is freely available and in the public domain.

Overall, the sense from our community respondents was that STEC/VTEC is not generally a well-known or well-understood disease. It was therefore suggested that infection prevention and control training, conducted for crèche staff on a regular and routine basis, could be instrumental in reducing the incidence of large STEC/VTEC and other communicable disease outbreaks in the future.

- No conspiracy theories about STEC/VTEC: unlike some public health measures – for example vaccinations – and in spite of the considerable economic and social disruption caused by STEC/VTEC outbreaks, efforts to control STEC/VTEC have not (yet) attracted any significant conspiracy theories which could undermine the effectiveness of response efforts.
Incident phase

The points identified below were reported to us as having emerged during STEC/VTEC outbreaks. The crèche that we visited is used as an example to illustrate some of the points raised.

- **Community response to STEC/VTEC:** when the crèche we visited was closed during the outbreak, some of the parents indicated that the public health authorities had over-reacted by closing the crèche, even though they were in fact following clearly prescribed national guidelines. A staff member told us that she tried to explain the reason for the closure to the parents, but they did not take the risk seriously. In support of this suggestion, staff members told us about children who had tested positive and negative continuing to play and share food together at home and at playgrounds during the closure. We also heard a report of a birthday party that included children who had been excluded from the crèche. The fact that nobody in this outbreak was hospitalised or developed HUS probably played a role in reducing the community’s STEC/VTEC-related risk perception.

- **Parental concerns about the financial implications of crèche closure:** as indicated above, on the day of its closure, the parents at the affected crèche were met by a public health doctor who explained the epidemiological situation to them, as well as what would be required before the crèche could be reopened. Bearing in mind that just two cases of STEC/VTEC had been identified at this stage, the overall response from parents was not so much about STEC/VTEC itself or its potential health impact, as about what the closure might mean for them financially. Some were extremely worried about losing their jobs, or about lost income if they were unable to organise alternative childcare arrangements and had to stay home with their children. Thus, the relatively low risk of a serious health outcome for their own child was outweighed in their minds by the moderate-to-high risk of a heavy hit to their family budget. This reflects the fact that although there may be no significant, adverse clinical outcomes in a given STEC/VTEC outbreak, even among those individuals who are infected, the measures required at community level to bring the outbreak under control are burdensome and can have significant social and economic implications.

In the event, the four parents we spoke to from the crèche (one with an STEC/VTEC-infected child, and three with STEC/VTEC-negative children) all struggled through the outbreak without any long-term financial consequences. Grandparents and neighbours were drafted in to provide support, and while the parents had to take some of their annual leave or unpaid leave to cover where grandparents were unavailable, their employers were generally sympathetic and supportive about the situation.

However, this is not always the case. Our HPSC respondents told us of cases during other outbreaks where parents had lost their jobs due to extended STEC/VTEC-related crèche closures. Furthermore, the parent of the infected child at the crèche we visited, whose infection lasted for several weeks and who was therefore excluded from the crèche throughout this period (as per national guidelines), spoke of the difficulties in planning for anything, particularly since it was an open-ended situation. This was especially challenging as, once the initial bloody diarrhoea passed, ‘she had no temperature, and she was in flying form’. It was not easy to stay home for weeks on end in order to quarantine an infected child who nonetheless seemed completely healthy.

Although adherence to the public guidelines is taken seriously by many parents, in spite of the financial cost this can impose on them, we also heard of cases where parents were either unable or unwilling to ensure that their children – infected or not – were kept apart from others, so that they could continue to work. For example, we heard of parents who, against the advice of the OCT, provided informal cover for each other on a rotating basis, whereby one parent would take care of a small group of children one day, another on another day, and so on. Thereby parents could continue working more or less uninterrupted. This generally happens (in the crèche we visited as well as elsewhere) when the children have been tested negative, but it reportedly also sometimes occurs even before the test results are back, which means that an infected – and potentially infectious – child could be playing and eating with uninfected children.

- **Community collaboration:** the crèche benefited from strong community collaboration and support during the STEC/VTEC outbreak when preparing for the deep cleaning that was required before it could reopen. It was in everyone’s interest to work quickly and effectively to prepare the building, and many local people gave their time and resources to facilitate this process. As one staff member said, ‘we were very motivated because we wanted to be back at work’. A nearby warehouse was made available for storing furniture and toys during the disinfection process, and staff members did an intensive initial clean-up prior to the arrival of the cleaning company, including painting some of the walls in order to ‘cover up’ any possible infection. Some people offered to provide laundry services for potentially contaminated towels and sheets, but the clinical nurse managers were obliged to put a stop to this in case it inadvertently spread the infection.
The recent STEC/VTEC outbreak in a nearby crèche provided an unexpected and fortuitous opportunity for peer-support during the main period of uncertainty at the start of the outbreak for the owner of the crèche we visited. The owner of the other crèche was ‘the biggest help in the early stages, telling us what needed to be done’. Similarly, some of the parents had family or friends in the area of the other crèche, and this helped them to understand what they might expect in terms of how long the closure could last, as well as its implications. Overall, the picture we received from the affected community was of exceptional, if unwelcome circumstances that brought people together in a positive way.

- Communications within and between affected communities and public health authorities: we observed a triangle of communications between the staff and owner of the affected crèche, the parents, and the regional public health authorities (this can also be seen in the stakeholder map in Figure 1). Here we discuss each of these three bi-directional communication relationships in turn.

  - Between crèche and parents: under routine, non-outbreak conditions, crèches tend to communicate with parents by text messaging, email, and social media platforms such as WhatsApp or Viber. In the event of any health alert in the crèche (e.g. diarrhoea, vomiting, chickenpox, head lice, etc.), parents are informed and preventive instructions are sent out as appropriate. For example, with a case of vomiting or diarrhoea a reminder may be sent out that children should not be sent to the crèche until 48 hours after the last event. Information notices may also be posted at the crèche that parents can read when they drop and pick up their children. In addition, some crèches use an app to communicate with parents, with information updated daily about their child: the number of nappy changes, how much food they ate, even how the child is feeling. Parents are therefore used to receiving a lot of information from the crèche.

  During the STEC/VTEC outbreak, the process of getting information out to parents from the crèche was described to us by one of them as ‘piecemeal’, and we were told that the crèche owners were ‘making it up as they went along’, even in the face of some parental hostility about the shutdown. Another parent told us that ‘they were doing the best they could ‘but they were learning as they went.’ The crèche owner also found it extremely demanding to have to handle numerous phone calls from parents, including questions about the closure and what they should do with their child. It is important to note that the OCT provided written instructions to the crèche about how to address the situation, and they were also in daily contact by phone – so different stakeholders appear to have had different perceptions about the support that was provided.

  - Between the public health authorities and crèche: we were informed that the Irish people generally have a high level of trust in the national level health authorities, including HPSC. However, the situation can be quite different for regional departments of public health, who are obliged to handle difficult issues at community level, and who sometimes need to take unpopular decisions based on very strong legislation. This context must be understood when considering the relationships and communications that can develop between the authorities and the community during an STEC/VTEC outbreak.

  As a basic principle, the importance of approaching the community in a collaborative and respectful manner was fully recognised by all our official institutional respondents at all levels. It was explained to us that while the regional public health authorities do have considerable legal powers, should they choose to enforce them, it is always easier for all concerned to bring a community on board by adopting a sensitive approach – ‘treating people as adults’, as one HPSC respondent stated – and by giving them simple, but complete explanations about what is happening.

  When an STEC/VTEC case is detected in a child, the protocol requires immediate and direct phone contact by the authorities with the parents. A surveillance form is then completed in order to collect the basic information that would be required in any epidemiological follow-up. The crèche owner is then contacted to inform them that one of their children has STEC/VTEC, and that active surveillance will be initiated in order to identify any further cases. If another case emerges, unless it is from the same family, the crèche will be closed. The crèche therefore knows in advance that closure is a possibility, so it will not be completely unexpected if it becomes necessary.

  In the crèche we visited, a meeting was held with staff and parents on the day of closure, at which a public health consultant from the region gave a brief talk about STEC/VTEC and its symptoms, why children and staff needed to be tested, and what control measures would be necessary. This was followed by a question and answer session. It should be noted that many parents (as opposed to staff) were unable to attend, and we were told by parents that a second meeting a few days later to further clarify the situation would have been very helpful. However, OCT staff were on site for two weeks to facilitate collection and co-ordination of specimen collection, and it was therefore possible to obtain information at the crèche during this period.
Once closure has been enforced, for logistical reasons crèche owners generally act as the intermediary between the public health authorities and the parents for the dissemination of information about STEC/VTEC, control measures, and updates on the outbreak. However, as indicated above, our institutional respondents reported cases of crèche owners being obstructive and even modifying information produced by the authorities for dissemination to parents, so that it was incorrect or otherwise misleading. (This was not reported in relation to the outbreak at the crèche we visited.) Tampering of this kind can have an adverse effect by inaccurately presenting someone or something as responsible or ‘to blame’ for the outbreak, and/or undermining trust in the activities that are required to bring it under control.

The crèche owner told us that she would have been grateful to have had just one contact person at the regional Public Health Department, as she ended up speaking to several different members of the Outbreak Control Team over the course of the two-week closure. While there was no problem with any of the individuals she spoke to, she found this particular issue to be frustrating and not conducive to good overall communications. However, OCT explained to us that they were seriously short-staffed, and since STEC/VTEC outbreak control was a very resource-intensive activity which added to their other ongoing tasks, it would have been impossible to have one dedicated person working solely on this issue. In addition, they had staff members on site daily for two weeks who were available to answer questions, and there was also daily email contact. As one OCT member explained, ‘I am not sure how much more communication or support we could have provided’.

Comments from some of the crèche staff members during our visit highlighted the sense of isolation that they felt, in terms of their own position during the outbreak. Referring to the regional authorities, one said: ‘They are public health, but they don’t talk to the public’. Another told us: ‘This interview [between us, the research team, and them, the staff] is nice. Normally we are not listened to, and normally decisions are made over our heads.’ Even though from their own perspective, the public health authorities did all they could with the limited resources available to them, it is nonetheless important to recognise the sense of isolation within the affected community – even if it was not universal.

The differing perceptions of these all-important contacts between the OCT and the crèche point to a critical area of community engagement: the authorities feel they are doing everything within their capacity to support the community, but some people still feel that they are not full partners in the response process.

Between the public health authorities and parents: because of the need to give out stool sample pots and verbal instructions to parents (and staff), as well as to receive and check the samples returned, health protection nurses are generally present at an affected crèche for several hours each day over the first two weeks of an outbreak. This essential, formal link between the authorities and the community also allows for an informal set of relationships to develop, which to some extent may ‘humanise’ the response in the eyes of the community, and create goodwill on both sides. As one nurse said: ‘we distribute bottles and give them information at the same time, and answer questions. [We can put] names to faces.’

One parent spoke of disturbing and contradictory advice about STEC/VTEC that she had received from different medical doctors that she had encountered in various settings during the outbreak. While a paediatric doctor had said that she could still take her infected daughter to the crèche if she was asymptomatic, a public health doctor had stressed that the girl should remain quarantined and not even play in public playgrounds. A third had told her that this was not true and that ‘there is no evidence for that.’ We were not able to ascertain whether the health workers in question were junior or senior, or what level of experience they had, if any, with STEC/VTEC. However, as health professionals who are trusted by the public, it is clearly essential that the advice given on this complex topic should be consistent.

Improved risk communication material for affected communities: our HPSC respondents identified a clear need for improved community health literacy in relation to STEC/VTEC as a pre-requisite for optimising control measures during an outbreak. One key challenge concerns parental understanding of the need to maintain strict STEC/VTEC control measures if their child has been excluded from crèche because they are infected, even though they continue to look and feel well. It was suggested that this could be addressed in a set of materials for the parents of infected children, highlighting the fact that although their child may not develop a serious illness from STEC/VTEC, he or she could still infect other children who could become very ill and possibly even die. Simple materials on hygiene issues could also be provided to new parents when their children join a crèche. Successful STEC/VTEC control requires a high degree of community solidarity, and calling on people’s best instincts may be part of this.
• Stool sample pots. Pots were handed out for free by the health protection nurses at the crèche during the first days of the outbreak: a total of 750 specimen pots were procured by the Department of Public Health for this outbreak, which should theoretically have allowed each person linked to the outbreak to submit five samples. However, there were reportedly challenges with the distribution of the pots after the crèche was re-opened, and some parents of children who were still STEC/VTEC-infected – and who therefore needed to provide samples regularly over an extended period – found that they were obliged to buy their own. This presented yet another logistical issue for them to address when they were already struggling with conflicting responsibilities involving childcare, other family issues, and work. A continuous supply of easily accessible sample pots for these few families would have been welcomed.

• Laboratory issues: The National Reference Laboratory (NRL) for STEC/VTEC is located at Cherry Orchard Hospital, just outside Dublin. They receive stool samples for testing from regional referral hospitals throughout Ireland, as well as from regional departments of public health. Stool samples are initially subjected to STEC/VTEC screening in primary hospital laboratories by either PCR (for VT1 +/- VT2) or culture. PCR-positive stool samples or E. coli cultured isolates are then sent to the NRL. However, in some STEC/VTEC outbreaks the primary stool sample is sent directly to the NRL for STEC/VTEC analysis.

At the STEC/VTEC NRL, confirmatory PCR for VT1 +/- VT2 is performed. If found to be PCR-positive, the sample is cultured in an attempt to isolate a viable STEC/VTEC bacterium. STEC/VTEC isolates then undergo full characterisation using Whole Genome Sequencing (WGS) in order to ascertain the genetic 'finger print' of the bacterium in question. WGS provides quick and highly-detailed information that helps the authorities to determine whether a set of cases are genetically clustered and/or epidemiologically connected. It can also determine if similar strains are present in food or water, and therefore whether the outbreak may be food-borne or water-borne. Validated cumulative outbreak results are sent (by e-mail or fax) urgently, often on a daily basis, to the relevant OCT and individual hard-copy results are also sent to the doctor (GP or public health doctor) who requested the sample. In accordance with Statutory Instrument 567 of 2018, infectious disease test results are uploaded to the Communicable Infectious Disease Reporting System (CIDR), to which laboratories and public health authorities throughout the country have access. Appropriate control measures can then be put in place.

We were informed by the NRL that the samples from the crèche we visited were coded and prioritised for processing, in accordance with their outbreak protocol. This was done even though the outbreak occurred during the summer holidays when many NRL staff were on holiday. The laboratory processed over 1 000 STEC/VTEC samples from different outbreaks over the summer, a heavy burden that required surge capacity arrangements involving regular rotation of personnel and a substantial commitment from all concerned. The flexibility and quality of the staff was noted as being key to the successful implementation of this process.

From a community perspective, several parents and crèche staff members spoke of their frustrations due to what they perceived as delays in receiving their results. The OCT’s protocol indicates that people at risk of infection should provide two stool specimens, approximately 24 hours apart, and that they (or their carers) are informed that they will be contacted if (i) they have provided two negative samples (in which case they are clear), (ii) one positive sample, or (iii) if the sample was mislabelled or the lab requests a new specimen. Unfortunately, it appears that there was some misunderstanding about this information. We were told by one parent that there was a different protocol for samples that tested negative and those that tested positive. He explained that ‘if you were negative, we were told that informing us would not be prioritised; but if you were positive, you’d be dealt with faster.’ Given the differing protocols for positive and negative samples – the results of one positive sample would indeed come through more quickly than the results from two negative samples – it is clear that there could be room for such an interpretation. Furthermore, since approximately 30% of the people who provided samples did so five days apart (instead of the requested 24 hours), the OCT informed us that some delays in providing these results were inevitable.

Thus, there was a mismatch between community expectations and what was technically possible. From the perspective of at least some people in the community, timeframes had become ‘nebulous’, and it was not possible for them to make plans, or to have any idea of when the whole experience would end and normal life could resume. Consequently, some parents started contacting the authorities themselves directly in order to get their results faster, but this appeared to become too burdensome for some staff. For some people, these difficulties also confirmed the sense of ‘us’ (victims of a serious disruption to their lives) and ‘them’ (the authorities), who did not take the victim’s legitimate concerns fully into account.
Post-incident phase

- Post-outbreak training for crèche staff: after the outbreak, the regional public health authorities held training for staff at the affected crèche and left them with materials about infection control. However, we were told that larger-scale training by HSE on the prevention of STEC/VTEC in crèches would be difficult to arrange, due to the currently unresolved question about responsibilities for public health issues in crèches, as discussed above.

- Post-event reviews: in order to document outbreaks properly, the details are generally written up in formal reports and this was done by the regional department of public health for the specific outbreak under investigation. These reports are confidential documents, though they may be accessed by the public in redacted form if requested through the Freedom of Information Act. They comprise an important part of the outbreak response, not least because there could be legal issues several years down the line in relation to a given outbreak, and it is important to have a formal record of what happened, both with regard to the outbreak itself and to the response. In addition, while the reports tend to conclude with clear recommendations based on the experiences garnered during an outbreak, various institutional respondents reported that these recommendations are not always subsequently acted upon. It was therefore suggested to us by our HPSC respondents that a review of STEC/VTEC outbreak reports could be conducted, and the recommendations synthesised into one document for dissemination to the regional departments of public health and for possible action.

During our own review of several STEC/VTEC outbreak reports, which came from more than one region of the country, we noted that the nature and extent of the community engagement activities conducted by health protection nurses in affected crèches are not given much focus. Neither is there any mention of the post-outbreak training that may have been given to staff. This may reflect the epidemiological and clinical focus of those who write the reports. However, the regional Outbreak Control Team that we visited responded positively to our suggestion that these community engagement activities could perhaps be systematically included in future reports. Inclusion in the report would not only be a means of formally recognising their importance as part of the outbreak response but also an acknowledgement of the work done by the health protection nurses at the crèche itself, and by the other OCT members who were intensively involved in taking calls from parents and staff.
Suggested good practices

This final section outlines a set of suggested good practices identified in this study that would promote community engagement in relation to STEC/VTEC outbreaks in Ireland. They are all based on suggestions made by our respondents, and they focus primarily on actions where improvements can still be made, as opposed to good practices that are already in place. These are presented as suggested objectives that may be worked towards, both by the authorities in Ireland and – where applicable – by those in other EU Member States that may be affected by outbreaks of acute gastro-enteritis in childcare facilities.

Promoting inter-sectoral collaboration and synergies between the health and non-health authorities

- Promote good cooperation: good cooperation from all sectors (health, agriculture and environment) was reported as the core factor that sustains effective STEC/VTEC response activities. This needs to be facilitated and nurtured to the extent possible. While collaboration between all the main health sector stakeholders was strong, additional measures, for example relating to hygiene inspections in crèches, could be of benefit.
- Facilitate strong individual relationships between key personnel: personal relationships between key individuals at many levels and in different agencies are key to the successful prevention and control of STEC/VTEC, at least in part because Ireland is a small country and people tend to cross paths over the course of their professional careers. While formal recognition of these relationships may be neither feasible nor desirable, they should nonetheless be facilitated and nurtured where possible.
- Synthesise recommendations from previous outbreak reports: a synthesis of the recommendations from previous STEC/VTEC outbreak reports along with an active dissemination process to the relevant authorities could help to ensure that the lessons learned from previous experiences are acted upon.

Promoting collaboration and synergies between the public health authorities and the affected communities

- Promote community health literacy concerning STEC/VTEC: efforts to improve community health literacy concerning STEC/VTEC, both in affected communities and more generally throughout the population, could contribute significantly to outbreak prevention and control, and would probably be welcomed by many. Information is already freely available in the public domain, but it needs to be accessed and used by those who need it.
- Ensure that documentation disseminated to parents and staff is in a ‘locked’ format: information materials that are sent to crèches for distribution to staff and parents should be presented as locked PDF documents, dated and signed off by the relevant authority, so that they cannot be altered.
- Streamline communication channels between public health authorities and crèche owners during an outbreak: conscious of the extreme pressures faced by the regional public health departments during an STEC/VTEC outbreak, it would nevertheless be valuable, if it were possible, to minimise the number of people with whom the crèche owner needs to communicate.
- Ensure that parents of children with extended STEC/VTEC infection receive a free and regular supply of sample pots: it is challenging for parents to have to buy sample pots from pharmacies when they are simultaneously having to deal with many other difficult issues related to their child’s infection. A free and accessible supply of sample pots from the public health authorities would also be a good way to maintain an ongoing relationship during a time when adherence to control measures could begin to slip.
- Provide support for families of children with extended STEC/VTEC infection: in cases where a child continues shedding STEC/VTEC for an extended period, it would greatly ease the situation for families – and promote adherence to control measures – if they could receive some sort of allowance to reduce the financial burden that this necessarily imposes upon them.
- Provide parents and staff with an estimated timeframe for the outbreak and aspects of the response, based on previous experience: crèche owners and parents need clear and unambiguous information about how long it should take for the collection and processing of stool samples, and for the cleaning and eventual re-opening of the crèche. Even if it is understood that such a situation is inherently open-ended, parents need to have some information or guidance to assist with their own planning.
- View the community as a real partner in the outbreak control response: people in the community want to be heard, and they want to be seen as genuine partners in the outbreak control process. Such partnerships are built on a transparent, two-way dialogue between the public health authorities and the affected communities.
- Include specific reference to community engagement activities in outbreak reports: systematically including details of the community engagement activities undertaken during an outbreak (including meetings, activities relating to samples, and the general provision of information) could promote a formal recognition of the importance of these activities as part of the outbreak response.
Other lessons learned not directly linked to synergies

- **Promote research into the key areas of scientific uncertainty concerning STEC/VTEC**: conducting scientific research to provide a stronger empirical basis for the closure of STEC/VTEC-affected crèches could facilitate a more targeted and less burdensome public health approach. This in turn would have a positive effect on community adherence to control measures.

- **Provide supplementary education on STEC/VTEC for health workers**: consistent advice from health professionals is essential if a community is to mount an effective response. Appropriate education for them is required in order to bring this about.

- **Ensure secure water supplies from private wells**: improving the standard and security of private wells would reduce the incidence of STEC/VTEC.

- **Facilitate the production of guidance for crèche owners whose facilities have been closed due to STEC/VTEC**: the production of an evidence-based guidance and support leaflet for crèche owners could greatly ease the pressures faced by both crèche owners and staff when they are closed down due to an STEC/VTEC outbreak. Such a leaflet could include a checklist or set of SOPs that indicate what a crèche owner may expect to happen over the course of an outbreak, who they should contact, and what other activities they need to consider undertaking during the period of closure, and when re-opening.
References


15. Health Protection Surveillance Centre (HPSC). VTEC. 2017; Available from: http://www.hpsc.ie/a-z/gastroenteric/vtec/


Annex 1. Schedule for data collection

Monday 26 November 2018
- Introduction to Health Protection Surveillance Centre staff
- National Public Health Veterinary Laboratory (DAFM). Group interview
- Health Services Executive (HSE). Interview
- HPSC Gastro-Zoonotic and Vector-Borne Disease Unit. Interview

Tuesday 27 November 2018
- National STEC/VTEC Public Health Reference Laboratory. Interview
- HPSC Communications. Interview
- HPSC Infection Prevention and Control. Interview

Wednesday 28 November 2018
- HPSC Gastro-Zoonotic and Vector-Borne Disease Unit. Group interview.
- Parents of children in childcare, non-STEC/VTEC-affected. Focus group discussion
- STEC/VTEC-affected childcare facility (owner and staff). Focus group discussion.

Thursday 29 November 2018
- Regional Department of Public Health, STEC/VTEC-affected region. Group interview.

Friday 30 November 2018
- Hot debrief

Week commencing 3 December 2018
- Phone interviews with parents from an STEC/VTEC-affected childcare facility.

Note: Individual participants are not named in order to preserve anonymity.
Annex 2. Interview and focus group questions

Two sets of questions were produced for this study: one for institutional representatives, and the other for focus group discussions with community representatives. Many questions are the same for both groups, allowing us to examine given issues from these different perspectives. The questions are presented below.

a) Questions for institutional representatives

Part 1: Mapping the different stakeholders

1. Please tell us how you and the institution you work for have been or are involved with the outbreak event.

2. Could you map out on a piece of paper the different stakeholders or groups that have been or are involved with preparing for and/or responding to the outbreak event? Which of these would you define as coming from the community, and which would you define as ‘authorities’? Do you think there are any stakeholders – institutional or from the community – who are missing from this map, 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

Pre-incident phase (prior to the outbreak)

3. To what extent were there any sort of public health preparedness exercises, consultations, or training activities involving both the community and the authorities prior to this case? Please describe these. Do you consider these activities to have been sufficient? If not, what could have been done in addition?

4. In general, do you think that the community trusted the public health and scientific authorities in this area prior to the event? Had there been any prior specific events (such as other disease outbreaks) that promoted or undermined trust?

Incident phase (during the outbreak)

5. Were there sufficient numbers of dedicated professional staff in the area available to respond to the case? Were there any problems, for example with funding, that may have limited the response?

6. Was there any official guidance for the authorities on how to engage with the community in this case(s)? What form did this guidance take?

7. Were the key actors in the community clearly identified and available when the case(s) first appeared? To what extent was there clarity about who was expected to do what?

8. What were people’s sources of information about the event (i.e. press and social media etc.)? How informative, coherent and consistent were these sources of information? Were there any issues that you think people felt they needed to know more about?

9. How was the communication and coordination between the community and the authorities during the response to this event [i.e. shared/democratic/top-down]? Were there any aspects that could have been improved?

10. To what extent did different parts of the community trust and cooperate with each other during the response to this event? Examples?

11. Were there any hard-to-reach or vulnerable groups? What efforts, if any, were made to reach out to them, by whom, and what lessons could be learned from this?

Post-incident phase (after the outbreak)

12. Was there any sort of post-case review of the event, including with reference to community-institutional collaboration? If so, what form did it take, who was involved, and what was the outcome?

13. 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

14. Overall, how would you describe (i) the community response and (ii) the official response to the event? Were you satisfied, or do you think some aspects could have been improved?

15. In general, how do you feel the community and the authorities collaborated during this event? What would you say was the most successful aspect of any collaboration? What were the main challenges faced in the collaboration process, and what efforts, if any, were made to overcome these?

16. 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?

17. Is there anything else you would like to add?
b) Questions for community representatives

Part 1: Mapping the different stakeholders

1. Could you map out on a piece of paper the different stakeholders or groups that you are aware of that have been or are involved with preparing for and/or responding to the norovirus outbreak event. Which of these would you define as coming from the community, and which would you define as ‘authorities’? Do you think there are any stakeholders – institutional or from the community – who are missing from this map, 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

Pre-incident phase (prior to the outbreak)

2. Are you aware of any sort of public health preparedness exercises, consultations, or training activities involving both the community and the authorities prior to this case? If so, please describe these. Do you consider these activities to have been sufficient? If not, what could have been done in addition?

3. In general, do you think that the community trusted the public health and scientific authorities in this area prior to the event? Had there been any prior specific events (such as other disease outbreaks) that promoted or undermined trust?

Incident phase (during the outbreak)

4. Were the key actors in the community clearly identified and available when the cases first appeared? To what extent was there clarity about who was expected to do what?

5. 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?

6. How was the communication and coordination between the community and the authorities during the response to this event? [i.e. shared/democratic/top-down?]. Were there any aspects that could have been improved?

7. To what extent did different parts of these community trust and cooperate with each other during the response to this event? Examples?

8. Were there any groups in the community who, for any reason, were excluded from the response? Details.

9. Were there any hard-to-reach or vulnerable groups? What efforts, if any, were made to reach out to them, by whom, and what lessons could be learned from this?

Post-incident phase (after the outbreak)

10. Was there any sort of post-case review of the event, including with reference to community-institutional collaboration? If so, what form did it take, who was involved, and what was the outcome?

11. 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

12. Overall, how would you describe (i) the community response and (ii) the official response to the event? Were you satisfied, or do you think some aspects could have been improved?

13. In general, how do you feel the community and the authorities collaborated during this event? What would you say was the most successful aspect of any collaboration? What were the main challenges faced in the collaboration process, and what efforts, if any, were made to overcome these?

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?
Annex 3. Informed consent form

Two versions of the informed consent form were used in this study: one for interviews with institutional representatives, and one for community members. The one used for the interviews with officials from the health/non-health sectors is presented here as an example.

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

*Study title: Enablers and Barriers for Community and Institutional Public Health Emergency Preparedness Synergies*

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

Two EU countries have been selected for inclusion in the case study, in agreement with ECDC and the countries concerned: Iceland and Ireland. Both of these countries were affected by disease incidents with acute gastroenteritis symptoms. These diseases will be the focus of the work which will seek to document the perspectives and experiences of key actors with respect to them in (i) the health sector; (ii) relevant non-health sectors, and (iii) in the affected communities.

Institutional: You have been identified as a representative of one of the official institutional categories that are considered as being critical in preventing, preparing for and/or responding to a disease outbreak. In addition to the health sector, our official institutional informants come from the education, agriculture, and environmental health sectors, as well as from the media.

Community: You have been identified as a representative of one of the community stakeholder groups that may have been affected by the disease outbreak, and as such we would like to invite you to participate in a focus group discussion with 5-7 other community stakeholders.

Your participation in the interview is entirely voluntary, and if you agree to take part, you are free to change your mind or withdraw at any time without consequences. If you agree to take part in an interview, any processing of your personal data will comply with Regulation 45/20015 and Swedish national law. ECDC is the data controller of this processing operation, and the data is collected and stored by the University of Umeå on its behalf, in its role as processor of the data. The interview will be conducted by two social scientists affiliated to Umeå University in Sweden, who are working with ECDC on the project. One member of the interview team will conduct the interview with you, while the other will take notes (either by hand, or on a laptop computer) and may ask additional questions.

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

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

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

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<th>Statement</th>
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<td>1. I agree to having my words used as quotes in the final report, and I understand that my words will be anonymised so that it will not be possible to ascribe any of my comments to me.</td>
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<td>2. I agree to having my name and institution included in an annex at the end of the final report listing the respondents who have contributed to this case study project.</td>
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Signature: ______________________________________________________________________
Name (in CAPITALS): ________________________________________________________________
Date: ___________________________________________________________

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5 Regulation (EC) No 45/2001 of the European Parliament and of the Council of 18 December 2000 on the protection of individuals with regard to the processing of personal data by the Community institutions and bodies and on the free movement of such data.
ECDC is committed to ensuring the transparency and independence of its work

In accordance with the Staff Regulations for Officials and Conditions of Employment of Other Servants of the European Union and the ECDC Independence Policy, ECDC staff members shall not, in the performance of their duties, deal with matters in which they may, directly or indirectly, have a personal interest that could impair their independence. Declarations of interest must be received from any prospective contractor before a contract can be awarded.