EUROPEAN CENTRE FOR DISEASE PREVENTION AND CONTROL

TECHNICAL REPORT

Community engagement for public health events caused by communicable disease threats in the EU/EEA

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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 the Amsterdam Institute for Global Health and Development, University of Amsterdam

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Abbreviations

AAR	After Action Review
ECDC	European Centre for Disease Prevention and Control
EEA	European Economic Area
EU	European Union
KAP	Knowledge, Action, Practice
PPE	Personal Protective Equipment
RIVM	National Institute for Public Health and the Environment, the Netherlands
SIMEX	Simulation Exercise
TBE	Tick-Borne Encephalitis
VTEC	Verocytotoxin-producing *Escherichia coli*

Executive summary

Introduction

This guidance document was developed in the context of EU Decision 1082/2013/EU on serious cross-border threats to health, and includes findings and guidance derived from an ECDC project on community preparedness (2016–2019). This comprised of a:

- a literature review
- case studies on community engagement during tick-borne disease events in Spain (Crimean-Congo Haemorrhagic Fever, or CCHF) and the Netherlands (Tick-Borne Encephalitis, or TBE), and on outbreaks of acute gastroenteritis in Ireland (Verocytotoxin-producing *Escherichia coli,* or VTEC) and Iceland (norovirus)
- an expert consultation on community engagement in public health emergency situations.

The resulting empirically-derived guidance on community engagement for public health emergency preparedness is intended for public health authorities in EU/EEA Member States. The guidance is meant to provide step-by-step technical support to Member States who are initiating or professionalising their core community engagement capacity. The guidance is organised according to the three core stages of the preparedness cycle: anticipation, response, and recovery.

Guidance for community engagement

These 14 guidance points were derived within a European context for public health authorities to engage with communities:

- Through all three phases of the preparedness cycle
  - 1. Recognise the community as a partner
  - 2. Develop understanding of community perceptions
  - 3. Optimise communications with at-risk communities
  - 4. Invest in a trusted spokesperson and long-term media relations.
- Anticipation phase
  - 5. Map stakeholders and integrate them into preparedness planning
  - 6. Develop an accessible and inclusive preparedness and response training program
  - 7. Cultivate relationships with communities engaged in disease surveillance
  - 8. Engage with pre-existing community networks and infrastructures
  - 9. Set research agenda in collaboration with community partners.
- Response phase
  - 10. Coordinate distribution of information, protective equipment and other resources for and with community partners
  - 11. If using an all-hazards approach, recognise the special character of infectious disease outbreaks, and act accordingly
  - 12. Facilitate resolving of possible issues with community-level financial losses.
- Recovery phase
  - 13. Integrate and document community engagement in evaluation processes
  - 14. Promote community debriefing, dialogue and a culture of shared learning.

Implementation

The implementation of the Guidance would require prioritisation, and adaptation of preparedness and response planning according to country-specific cultural, epidemiological and political contexts, and according to the specific mandates of public health authorities. Community engagement requires skilled practitioners, dedicated to fully engaging and integrating with the preparedness and outbreak control team and supporting implementation of the community engagement concept. It is important that community partners feel ownership of the implementation processes, which will most likely lead to more sustainable and effective outcomes in the long term.

Introduction

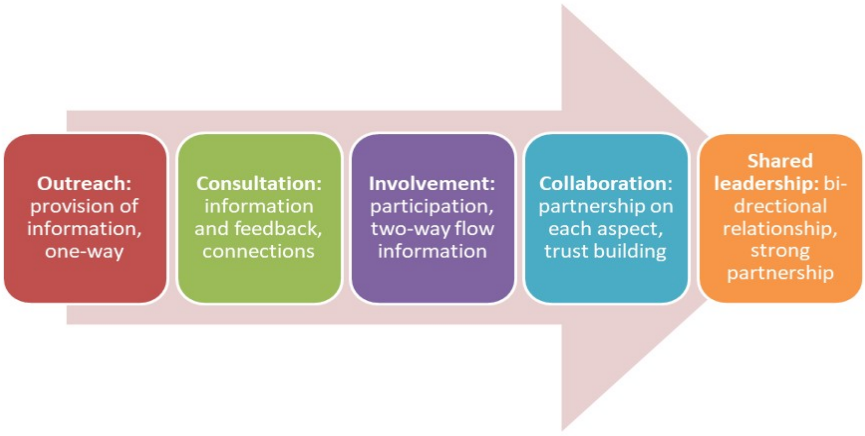
Aims and objective

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

As part of the process of optimising preparedness for serious cross-border public health threats (in the context of implementing Decision 1082/2013/EU), the European Centre for Disease Prevention and Control (ECDC) conducted a project on synergies between communities affected by public health threats, and the institutions (both health- and non-health-related, and at both the national and the local or regional levels) mandated to prepare for and respond to them. The premise for the project is that communities are increasingly recognised as key partners that can be engaged with during public health emergencies [2-4], and that the capacities and experiences that reside within community networks should be harnessed as an important part of the response [5]. Similarly, it is important to understand how, and the extent to which, institutions in the health and relevant non-health sectors can collaborate in such community-oriented work.

We define 'community' as not only at-risk groups who are physically or geographically affected by public health threats including infectious disease outbreaks and public health emergencies (or health related events that go beyond normal circumstances and require additional resources to be dealt with), – but also as those stakeholders who are linked to these affected populations and who may be able to assist in the process of solving or mitigating the problem [6]. Such actors may already exist in the civic or public realm in the form of potential stakeholder groups (such as religious communities or labour unions), each with their own interests, sub-cultures and specific expertise, or they may emerge during emergency events in the form of new coalitions (such as patient associations). Engaging these communities is a process that moves along a continuum, from involvement of community-based partners and at-risk communities in the exchange of risk information, to the gradual development of longer-term partnerships with shared decision-making that can address a wider range of social, economic, political, and environmental issues relating to health. Figure 1 illustrates this continuum in which the arrow reflects the increasing levels of trust and engagement that can develop.

Figure 1. Levels of community engagement (Adapted from [7])



This document is a strategic guidance built on generic principles to be operationalised in specific country-system contexts, according to local, regional and/or national requirements and jurisdiction. Since resources can be limited in many settings, it may be useful to consider whether a comprehensive or a selective approach to community engagement should be taken.

This process can take into account several factors, including the potential public health impact of a given event, the level of public interest, as well as feasibility and resource issues, depending on local needs and possibilities.

This guidance document was derived from empirical data collection and analysis with a focus on public health events caused by communicable disease threats (in accordance with ECDC's mandate, aiming at communicable disease prevention and control at the EU-level) in four EU/EEA countries. However, the generic framework for action options can also be applied to other disease and geographical contexts, depending on the availability of resources. Furthermore, EU countries maintaining traditionally intense commercial relations and migratory flows with non-EU countries might consider to paying special attention to these communities of non-EU origin.

Decisions regarding levels of participation by responsible authorities both at the national and at regional/local levels depend on program objectives, contexts and other considerations, such as how much decision making an officially mandated authority is willing and able to devolve [8]. The key operational principle in community engagement is the building of trust, which is important in all phases of the preparedness cycle but has proven to be of immense value during the anticipation phase, which then leads to smooth relationships during crises, when community stakeholders can provide critical support and guidance [5].

Community engagement might require specific skills and technical expertise, for which this guidance document provides a road map of actions for consideration at the institutional level to start a process of community engagement (incl. selected reference links to other guidance documents for more in-depth detail). It includes findings and guidance points derived from:

- a literature review,
- case studies on community engagement (during tick-borne disease events in Spain (Crimean-Congo Haemorrhagic Fever, or CCHF) and the Netherlands (Tick-Borne Encephalitis, or TBE), and on outbreaks of acute gastroenteritis in Ireland (Verocytotoxin-producing Escherichia coli, or VTEC) and Iceland (norovirus))
- an expert consultation on community engagement in public health emergency situations.

The findings are organised based on a theoretical preparedness cycle that includes **anticipation, response** and **recovery** [9]. Within this theoretical preparedness cycle [10], the anticipation phase involves preparation and planning; the response (incident) phase involves management, monitoring, investigation, and intervention; and the recovery phase involves post-incident assessment and identification of lessons learned.

Target audience

This guidance is intended to provide technical support to public health authorities in Member States who initiate or expand their core community engagement capacity. All guidance points are presented as options for actions that should be considered for prioritisation, both at national and regional level. (depending on the wider context, the nature of the public health event in question, the communities affected, and the mandate of the public health authorities).

Sources of evidence

The sources of evidence for this guidance include a literature review, case studies and an expert consultation. More details on evidence is in Annex 1. In 2016 a literature review was conducted following PRISMA guidelines that identified enablers and barriers to community and institutional synergies in emergency preparedness [5, 11]. In 2017 and 2018 case studies were conducted in four EU/EEA countries: Spain, the Netherlands, Iceland and Ireland. All case studies were based on qualitative sources of evidence using a rigorous and systematic approach that incorporated the findings of the literature review including:

- document and media review
- semi-structured interviews and focus group discussions with community representatives and with a range of technical experts working at national and regional levels
- and a stakeholder mapping exercise.

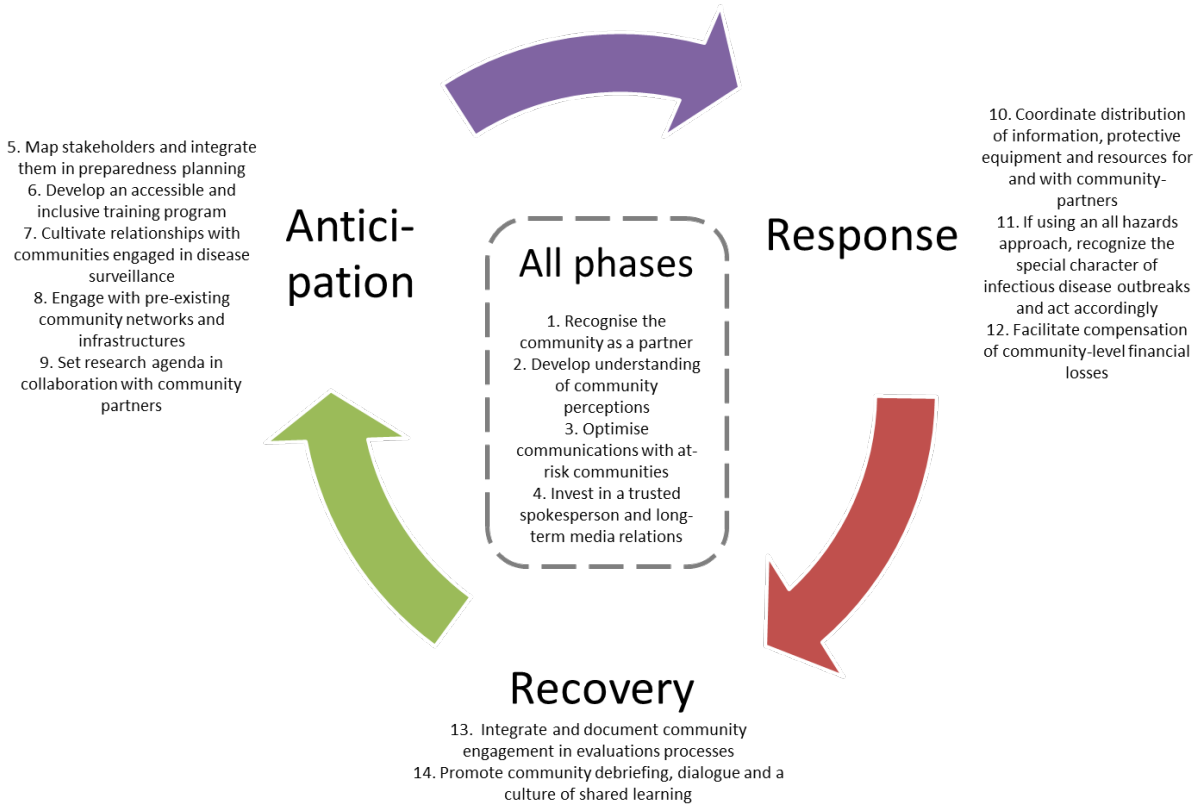
Following the quality criteria of Guba and Lincoln for qualitative evidence [12], the trustworthiness of the empirical findings from the case studies was deemed sufficient for evidence-based guideline development. Based on the empirical findings of the case studies and the results of the literature review, a draft version of this guidance document was critically reviewed at an expert consultation meeting in March (27–28) 2019. Participants at this meeting included 20 international community engagement actors, technical experts, and ECDC stakeholders, including the National Focal Points for Preparedness and Response from the four countries that participated in the case studies. The consultation collected feedback on the content and preferred format of the guidance document using a systematic process that prioritised expert evidence over opinion [13].

Guidance for community engagement

The content of the guidance is based on sources of evidence including a literature review, case studies and an expert consultation (see Annex 2). All of the following 14 options for action were derived empirically from the field work of the case studies, informed by the findings of the literature review [5, 11], and further refined during the expert consultation.

The suggested options for action are presented within the three-stage preparedness cycle. Five of these appear in all three phases. The options for action are not presented in any perceived order of importance. Figure 2 provides an overview of the preparedness cycle with an indication of relevant options for action.

Figure 2. The guidance points according to the preparedness circle



Options for actions relevant to all three phases of the preparedness cycle

Recognise the community as a partner

Community members need their voices t heard in the outbreak preparedness and response process, and want to be seen by the authorities as genuine partners. Indeed, public health authorities invariably do all they can to prepare and respond in a timely and effective manner to an outbreak. In times of emergencies, community members might sometimes feel isolated from the decision-making process. Therefore, viewing the community as a partner and a resource for optimising preparedness planning, response and recovery actions is a key aspect of a fruitful collaboration. An informed, at-risk community understands the challenges to adopting effective preventive practices. Through dialogue with well-placed community representatives, areas for improvements can be identified and valuable contributions made to outbreak management during all phases of an outbreak event.

For example, local or regional After Action Reviews (AARs) are an effective means to learn, listen and share experiences of community-based partners who have supported response coordination. Community partners should be heard, and this may soften emotional grievances and facilitate possible issues with financial losses for the communities. By keeping the principle of community partnership at the core, public health authorities can enable community members and groups to be recognised and to define themselves as partners who shape their own roles and identities in the process. This leads to long-term trust, which although it takes time, contributes to commitment, and building of sincere relationships, which is an essential component of any successful preparedness, response and recovery programme.

Options for actions

- Be willing to be open to community input:
  - Avoid being too directive or restrictive in leadership: be willing to allow community stakeholders to take control of some processes, and be open to input on others.
  - Examine the way public health professionals view and discuss community participation. Institutions may not always recognise the capacities of communities from the outset. Hold open and honest discussions to adapt organisational cultures when and where needed.
  - Maintain transparency and clarity on expected outcomes of the community engagement process.
  - Try to ensure availability of flexible preparedness cycle funding schemes for the population targeted, to be implemented where the community feels it is most worthwhile.
- Conduct sensitive and community-appropriate outreach:
  - Use a professional in a leadership position consistently, whom citizens can contact for information or support.
  - Hold meetings when convenient to citizens.
  - Consider language issues and jargon; make communication accessible and culturally sensitive.
  - Identify priorities and needs in conjunction with the community and ensure that they are well understood and included in any preparedness cycle project.
  - To build trust and broader understanding, emergency personnel should be encouraged to participate in relevant non-emergency management community meetings, such as business continuity-related exercises, community fairs and sport events or inviting people to open house events at emergency operations centres.
- Empower communities:
  - Help community members recognise that they have an important role to play in creating a collective support structure, and that this goal is realistic. This can be achieved by assigning formal roles to members of the community at a grassroots level (e.g. communications liaison, social media monitor).
  - Work and train communities to engage in joint decision-making, to build enough capacity for communities to be able to use the funds held by government systems.
  - Consider that community members often do not know how to navigate between governmental structures, which at times might be quite bureaucratic, and may need support doing this. Offer the opportunity during the anticipation phase to learn required skills and capabilities to empower community partners to effectively engage in collaborative work with the public health authorities at national and local levels.
  - Motivate already engaged community members to develop and take on roles in peer-support structures.
  - Provide opportunities that facilitate self-empowerment and inclusion to socially-excluded citizens.
  - Mediate contrasting views within communities, possibly with the assistance of external expertise. Set up safe forums where such tensions can be openly discussed.
- Provide feedback on successes:
  - Focus on celebration of early successes in the initial stages to provide momentum and energy for more members to join. Share success to build communities' trust in the engagement processes and to trigger dedication to push through difficulties.
  - Communicate to citizens how their input is being used and how it contributes to successful outcomes.
  - Disseminate success stories internally to motivate institutions leading the response to use community input and understand its value.

Further information

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Develop understanding of community perceptions

Systematic efforts are necessary to understand community perceptions of any public heath incident, including perceptions during the anticipation phase, using social media, rapid assessments, or by documenting the topics of concern raised on dedicated telephone hotlines. For example, community members may perceive that authorities do not understand them, see scientists as aloof and authoritative, or feel that short-term external aid ignores historical context of past injustices or continuing inequalities. Monitoring community perceptions enables authorities to respond to misinformation or rumours about an issue that may emerge throughout the population, but it may also allow for better understanding of the logic behind community attitudes. Efforts to improve community health literacy through this process, specifically among hard-to-reach, vulnerable and at-risk communities, could contribute significantly to outbreak prevention, response, and recovery.

Options for actions

- Listen 'actively' to the concerns of key stakeholders. What may seem irrelevant or even irrational from a biomedical perspective probably has logical reasoning from another point of view and may need to be addressed. Solicit the advice of cultural mediators, if needed.
- Use a diversity of means to 'listen', including media and social media surveillance, obtaining public opinion through surveys, influencers or rapid social science research.
- Develop an understanding of what community partners and citizens think and who they trust, to understand their priorities, and to ascertain through which channels to reach them.
- Determine what important information and knowledge is held by which community entities or individuals, and determine the extent to which it is shared with others.
- Understand to what extent community groups may use different language for the same issue and understand how this may hinder effective collaboration.
- Provide people with relevant information - promptly, transparently, and completely - to avoid rumours developing. Silence increases ambiguity and confusion, while simply denying a rumour does not eliminate ambiguity; it may even increase it. Address the rumour directly where needed, using credible spokespersons and speakers.
- When an outbreak occurs, be ready to conduct quick formative research, such as Knowledge, Action, Practice surveys (KAP), interviews or observations, if possible in collaboration with relevant community stakeholders. Determine what tools would be best to use so that you can mobilise community groups quickly, which can complement efforts by doing their own research.

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Optimise communications with at-risk communities

To ensure that community-based actors are properly equipped to prepare for, respond to, and recover from disease outbreaks, they need to be informed about many aspects of the disease in question, as well as the response actions to it designed by the public health authorities. To this end, it is important to facilitate the production, elaboration and implementation of actions listed in guidance documents. This should ideally be done in collaboration with civil society organisations with links to at-risk communities, if appropriate.

It is also important to apply audience segmentation in risk communication as different communities may perceive a given health threat in different ways, have different health literacy levels, and be different in the way they respond to control measures that are implemented. This has implications for any risk communication strategy.

Wherever such divided perceptions are found, the different populations should be targeted with different messages or languages, and possibly disseminated via different channels. For example, when considering tick-borne diseases, there might be several hard-to-reach or vulnerable populations and groups to have in mind. These include pet owners, scouting group members, children at school or day-care, garden owners, volunteers working in green areas, hikers, tourists (local or foreign) or asylum seekers who live in forested areas. These groups are often disconnected from general prevention campaigns and from regular and systematic registration, surveillance and monitoring systems.

Options for actions

- Collaboratively develop guidance documents. Such documents could include a checklist or set of Standard Operating Procedures that indicate what communities may expect to happen over the course of an outbreak; an estimated timeframe for the outbreak; who they should contact and under what circumstances; and what other activities they may need to consider undertaking during the outbreak and the recovery period.
- Conduct outreach based on an understanding of the health literacy levels, cultural issues, socio-economic differences (e.g. rural-urban divide), or competencies and norms of the community. Always consider the ideas, concerns and expectations of the community. For example, in some communities, certain approaches to predict emergencies and disasters might be considered as taboo subjects due to, for example, religious reasons. If possible, establish ways to address such communities by using their language and translating your concerns into their worldview. Obtain the help of people who are part of such communities or cultural anthropologists to accomplish this.
- Get in touch with community leaders to reach out to the community. Know who they are and how they position themselves in accordance with your goal (by utilising the concept of a stakeholder mapping). Note that healthcare workers are both influencers and target groups.
- Be open to non-traditional outreach strategies such as those suggested by people from inside the community (e.g. organise a bicycle race that includes outreach regarding tick bites).
- Communicate clearly with the community about ongoing processes during each of the different phases of an outbreak or event. For example, provide updates on investigations, even if results are not yet conclusive. Trust is a vital factor in communication. Giving more information rather than less tends to improve adherence to a public health strategy, while also building trust in a community.
- Adjust communication strategies according to the preparedness and response cycle: certain communication methods that are effective during the anticipation phase, for example, may not be effective in response. While in preparedness mode, community partners can lead communication efforts, during emergencies the responsibility and lead for communication should fall on the responsible public health authorities.
- Involve social scientific expertise in the development of messages, and pilot these messages in small groups before rolling out to the larger population.
- Think about approaches to integrate information dissemination through existing community services, e.g. agricultural extension services to deliver information to farmers.
- Ensure that operational personnel and technical experts receive all the relevant information as soon as it is obtained and validated so they can respond to questions from community partners or members.
- Be aware that information collected from surveys, focus groups and interviews is sometimes stored, but not analysed or shared, due to time or capacity limitations. As a result, valuable information may be lost, but also community expectations of being heard may be missed, which can break trust. If possible, enlist volunteers' help to support further analysis. This can include community members, if confidentiality rules are adhered to.
- Develop a multi-method approach to sending emergency messages, as not all households will have access to all forms of media, and language issues and disabilities may be of concern. Mainstream television could broadcast alerts that contain visual images to increase awareness of any changes to the environment. Word of mouth communication can be combined with visual information as a reinforcement.
- Consider disaster awareness and preparedness training for interpreters, bilingual staff, and people with sensory impairments.

Further information

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Invest in a trusted spokesperson and long-term media relations

To ensure that communities are properly equipped to prepare for, respond to, and recover from an outbreak, people need to be informed about many aspects of the disease in question, as well as the response to it. It is therefore important to provide authoritative health information to the community through a consistent spokesperson who is trusted by the different sectors, community partners and the general public, and who can become the 'public face' of the official public health response. In addition, it is important to build trusting relationships with journalists outside of emergency situations as this could benefit both sides. Journalists can be important sources of information for what is going on in the community, while also disseminating key information to at-risk populations. This, however, requires transparency on the side of public health institutions.

Options for actions

- Develop a trained cadre and retention strategy for trusted spokespersons, including back-up staffing.
- Ensure communication guidelines are in place.
- Be timely and accurate.
- Identify influential media, including traditional media (international, national and local) or bloggers/free lancers.
- Include key media people in risk assessments and train them on public health issues beforehand, so when there is an event they already have an understanding of how a situation may develop and how authorities plan to be handle it.
- Coordinate to ensure that there is one voice reaching actors involved providing a clear message and disseminating agreed talking points. Make sure journalists know who the key people are so that they can reach out to them when needed.
- Think about which channels to use to disseminate complex information.
- Beware of information vacuums in which rumours can develop; attempt to have regular updates, even when there is no real news. When using social media, it is important to update information flows regularly.
- Prepare contingency plans for the press offices of local (provincial/ municipal) health authorities who may need support in responding to high volumes of press interest in the event of a serious outbreak.
- Translate your messages to other language(s) to facilitate international media, if needed.
- Collect and regularly review the published information in the press to observe accuracy and any needs for providing complementary information. Bring key actors together to reflect together on what is happening. Acknowledge owners of communication messages and allow them to take a lead (if appropriate) or at least being part of the team working on information dissemination.
- Identify when the incident is over, have a final meeting with the regional epidemic response team, and draft a press release to make this explicit.

Further information

- ECDC. A literature review of trust and reputation management in communicable disease public health. 2011. Available at: https://ecdc.europa.eu/en/publications-data/literature-review-trust-and-reputation-management-communicable-disease-public
- WHO. Effective Media Communications during Public Health Emergencies: A WHO Handbook. 2005. Available at: http://www.who.int/csr/resources/publications/WHO_CDS_2005_31/en/
- CDC. CERC: Working with the media guide. 2014. Available at: https://emergency.cdc.gov/cerc/ppt/CERC_Working_with_the_Media.pdf

Anticipation phase

Map stakeholders and integrate them into preparedness planning

Collaboration during an infectious disease outbreak between communities and authorities is more likely if community members have been actively engaged and given ownership in the development of preparedness plans during the anticipation (pre-incident) phase. Early mapping and participation by a representative cross-section of stakeholders, including representatives of at-risk and vulnerable or hard-to-reach populations is therefore desirable. This increases ownership and 'buy-in' on behalf of community partners, and facilitates collaboration and adoption of needed practices, behaviours or technologies, as well as the inclusion of newly-emerging relevant community partners.

As during an infectious disease outbreak, each stakeholder manages their own environment and works with their own networks. Working together during the anticipation phase to clarify roles would facilitate a smooth and coordinated response. A stakeholder analysis is needed to identify key partners as during an outbreak, one organisation cannot accomplish everything itself, and instead a network of organisations may need to collaborate to reach the common goal to successfully contain health threats.

Involvement of community-based actors in such networks is also important to identify and address issues with a longer-term perspective - e.g. psycho-social care, etc. These aspects of public health tend to be more social and less operational, but they directly address community-level needs and priorities. Furthermore, a multi-sectoral approach (such as One Health – recognising the interconnectedness of human and animal health as well as environmental factors[i]) needs to be used to map out linkages between the various stakeholders and their associated community-based partners.

The activities in anticipation phase include:

Risk ranking: Risk ranking is an initial step in strategic public health planning, with the key objective being the prioritisation of preparedness activities. There is value in the risk-ranking process itself because it brings together stakeholders and practitioners from diverse fields to promote interdisciplinary working. However, inclusion of community-based partners could be considered as well, because participation makes the process more democratic, lends legitimacy, educates and empowers the affected communities, and generally leads to decisions that are more accepted by the community. Affected community members can contribute essential community-based knowledge, information, and insight that is often lacking in expert-driven processes, while also assisting in dealing with perceptions of risk and educating their network about different types and degrees of risk. For example, surveys of community partners could be used to identify criteria for ranking, or to provide weights to ranking criteria, thereby contributing 'lay' input into the expert process.

Stakeholder and resource mapping: Based on the risk ranking outcomes, conduct a comprehensive mapping of community-based stakeholders, including those representing vulnerable/hard-to-reach and at-risk populations (see an example in Annex 2). Community-based stakeholders are entities (organisations, platforms, networks, or groups) that could have some form of influence on preparedness planning response and recovery, because they have something to gain or lose through the outcomes of these planning processes or projects. The mapping process includes identifying the stakeholders, differentiating between or categorising stakeholders, and analysing relationships between stakeholders. In addition, gathering information on available resources and competences held by these stakeholders, as well as their logistical and knowledge gaps, and training needs should be considered.

Stakeholder verification and adjustment: The list of stakeholders will never be exhaustive or comprehensive and will also remain dynamic. Some groups are very heterogeneous, such as hikers, while others are more defined. As a result, stakeholder mapping needs to be ongoing, recognising these dynamics. Regular consultation is needed to identify stakeholders and verify the mapping for each specific public health threat caused by the communicable disease

Facilitate access to information for contact tracing and reaching vulnerable/hard-to-reach risk groups: Focus on the identification of vulnerable/hard-to-reach/at-risk populations. Stimulate a sense of shared responsibility between public health authorities and community actors regarding exchange of information on vulnerable, hard-to-reach or at-risk groups in anticipation of a given health threat, thereby facilitating contact-tracing and follow-up as necessary. The EU's General Data Protection Regulation should of course be taken fully into consideration in any such effort.

[i] See, for example: https://ec.europa.eu/health/amr/sites/amr/files/amr_action_plan_2017_en.pdf

During a public health event, however, public authorities lead activities on the contact tracing and exchange of information between concerned individuals and other relevant cross-sectorial institutions without further devolution of responsibility to community-based actors. When conducting contact tracing to potentially exposed individuals and performing follow-up actions, protocols should be sufficiently flexible to consider differences in community characteristics.

Early integration of community-based stakeholders in preparedness planning for outbreak response: Include community stakeholders from the beginning of the process to elaborate preparedness planning (either generic or specific). When there is a need to adapt a generic plan, stakeholder mapping should be conducted again as soon as possible to reflect on and adapt the plan to a specific emergency incident and to include newly emerging community-partners. Early inclusion motivates ownership already in the planning process, prompt engagement and collaboration in the emergency phase, including volunteering practices and building long-term trust. It is equally important to be involved in the process for developing a plan, to have a finalised plan and to be part of its implementation.

Working together in the planning process stimulates the sense of belonging to a wide community and having ownership of planned activities. Therefore, it is important for public health authorities to think about how to communicate with the community and, facilitate the common understanding on what to do if emergencies develop. Risk and impact analyses as well as contingency planning should be combined with training and awareness raising. Including long-term recovery initiatives in the preparedness plans could further motivate community members to be engaged, as these aspects are closely related to social concerns and community needs.

Options for actions

- Consider participation of key community-based partners in risk ranking:
  - Make sure community-based partners involved in risk ranking have the knowledge to understand the technical issues and access necessary documents.
  - Engage stakeholders in the classification and categorisation process. Try to include people across sectors. Carefully balance the harm of exclusion and the benefits of inclusion of community-based actors who do not primarily serve public health but may have interests at stake, such as for-profit actors. Make note of new groups—previously not considered a 'community' or 'network'—that may emerge in the incident phase and include them in subsequent mapping or debriefing.
  - Repeat risk-ranking exercises at regular intervals given the rapidly changing public health landscape. The choice of methodology should reflect the purpose of the risk-ranking exercise.
- Conduct stakeholder and resource mapping:
  - Determine the right person to contact relevant stakeholder groups. In some contexts, someone at the national level may not easily know regional groups.
  - Conduct the mapping collaboratively. This can be done either by taking the lead in the development and sharing of a first draft to community stakeholders for further feedback and input, or - and this is the preferred option for developing stronger ownership - by developing community initiatives in which community partners drive the mapping processes that could be accepted and signed off by government.
- Ensure ongoing stakeholder mapping verification and adjustment
  - Make verification and adjustment a regular agenda item at preparedness, incident and recovery meetings by asking with whom stakeholders worked in the past or with whom they would work in the future during an outbreak. It is also important to establish which are, from their point of view, the most trustworthy sources of information.
- Solicit the support of community partners to create registers for contact tracing and vulnerable/at risk-groups:
  - When creating registers together, monitor individual rights to privacy. Adhere to legal restrictions, yet also maintain an ethic incorporating a do-no-harm principle. This means a careful balancing of public health needs and individual rights.
  - Establish legal rights to data sharing.
  - Facilitate ways to support obtaining funding by community-based organisations who focus on vulnerable populations.
- Integrate community-based stakeholders early in preparedness planning:
  - Try to ensure that sufficient resources are dedicated to the coordination of community involvement throughout the process.
  - Take community risk perceptions and anxieties into explicit consideration when developing emergency preparedness strategies, and provide ample feedback to community partners about reasons why decisions are made.
  - Ensure that stakeholders from different sectors are facilitated to work together.
  - Develop a protocol in advance of any zoonotic public health incident that includes provisional agreements with all relevant sectors for establishing a 'One-Health' crisis committee.

- Conduct briefings with stakeholder groups, discuss what has been learnt from previous outbreaks and what may be needed for stakeholders to support the response and the broader community.
- Be aware that relevant groups of individuals may be left out of community meetings, for example, due to long distance for travel or a lack of childcare. Also, some existing preparedness procedures only relate specifically to those directly in the vicinity, such as workers, and not the wider public.
- Include vulnerable populations, such as communities with sensory impairments, in preparedness activities to understand their needs better.

Further reading

- ECDC. ECDC tool for the prioritisation of infectious disease threats. 2017. Available at: https://ecdc.europa.eu/en/publications-data/ecdc-tool-prioritisation-infectious-disease-threats
- National Research Council. Community Involvement. In: A Risk-Management Strategy for PCB-Contaminated Sediments. 2001. Available at: https://www.nap.edu/read/10041/chapter/6
- Overseas Development Institute. Planning Tools: Stakeholder Analysis Toolkits. 2009. Available at: https://www.odi.org/publications/5257-stakeholder-analysis
- WHO. Sample Stakeholder Mapping Grid. 2018. Available at: https://www.who.int/reproductivehealth/stakeholder-mapping-tool.pdf
- NHS Improvement. Stakeholder analysis Online library of Quality, Service Improvement and Redesign tools. 2018. Available at: https://improvement.nhs.uk/documents/2169/stakeholder-analysis.pdf
- M.S. Reed & R. Curzon, Stakeholder mapping for the governance of biosecurity: a literature review. Journal of Integrative Environmental Sciences Volume 12, 2015 - Issue 1. Available at: https://www.tandfonline.com/doi/full/10.1080/1943815X.2014.975723
- European Commission. 2018 reform of EU data protection rules. 2018. Available at: https://ec.europa.eu/commission/priorities/justice-and-fundamental-rights/data-protection/2018-reform-eu-data-protection-rules_en

Develop an accessible and inclusive preparedness and response training program

Community-based actors – identified based on their specific leadership qualities, capacities or personal skills and experience – need to be included in training and development of response training materials. Training could be conducted on a routine basis, but also as refresher courses. Health workers also need to be well-informed to provide consistent advice to the community. Regional authorities and community-based volunteers need easy access to training materials and guidance on any type of infection prevention and control measures, such as personal protective equipment (PPE), cough and hand hygiene, routes of transmission, etc. Training could include publicly available video-based instructions on using PPE, landscape management suggestions to reduce the presence of ticks, or lists of competent (or certified) parties who can clean premises that may have been contaminated during an outbreak of gastroenteritis. The need for simulation exercises (SIMEX) is more acute when there is little historical experience with outbreaks. Simulation exercises need to include a community engagement component and community level response partners. Training on the role of community stakeholders when there is more than one incident at the same time should also be considered.

Options for actions

- Identify which knowledge and skills are lacking through a training needs assessment, including consultation of previous after-action reviews and experienced experts.
- Identify and support community-based initiatives that are relevant to training needs.
- Explore internal and community-based capacity for conducting training, and develop lists of trainers and people to contact for training needs.
- Consider having community members participate in training development, to facilitate inclusion of issues that are of community concern, including during simulation exercises.
- Decide what type of training is needed and how community engagement concerns are included in the training or simulation exercise.
- Include multi-sectoral partners in training and simulation exercises to develop awareness of the value and dependencies across sectors.
- Decide if the training is highly recommended for community partners for them to take on certain roles in preparedness and response.
- Think about how to reward and acknowledge training participation, e.g. if credits or certificates can be given.
- Develop and conduct an evaluation of the training or exercise. Consider whether and how to include community actors in the evaluation process, as well as the possibility of conducting a longer-term follow-up to assess impacts.

Further reading

- ECDC. Training on infection control in the EU/EEA. 2015. Available at: https://ecdc.europa.eu/en/publications-data/training-infection-control-eueea
- WHO. Infection prevention and control Evidence, guidelines and publications. 2019. Available at: https://www.who.int/infection-prevention/publications/en/

Cultivate relationships with communities engaged in disease surveillance

Community engagement in disease surveillance has a long history, and it has proven to be critically important in disease outbreak detection in some settings. For example, zoonotic researchers often work in close collaboration with a host of partners from parks, nature reserves and agriculture (e.g. land owners, estate managers, hunters, herders). Citizen science initiatives which are explicitly focused on obtaining surveillance and research data through public participation are also excellent mechanisms for even broader collaboration, and, when in the form of online platforms (e.g. the Dutch online 'Tick Radar'[ii]), can also provide the added benefit of disseminating risk communication messages. It is, however, important to provide community actors who contribute relevant data or information for surveillance and other preparedness activities with feedback about coordination, response activities, and any relevant decisions that are made based on the data. People tend to be more collaborative with authorities if they receive regular updates on the usage(s) of the datasets to which they are contributing.

Options for actions

- Identify and engage actors who may collect data, e.g. through citizen's science projects or passive data collection systems. Identify and promote community initiatives.
- Develop a mechanism for data sharing. Consider who owns the data if collection is supported by private actors.
- Think about how data can be standardised across platforms and classifications.
- Be sure to comply with regulations regarding privacy and confidentiality, including issues of secure data storage.
- Identify actors who can help with contact tracing.
- Consider options to provide resource support for analysis of data to which community partners contributed, if applicable.
- Develop mechanisms to provide feedback about data collection and analysis back to the community actors, particularly to those who directly contributed.

Further reading

- European Citizens Science Association. A collection of Citizen Science guidelines and publications. 2017. Available at: https://ecsa.citizen-science.net/blog/collection-citizen-science-guidelines-and-publications
- Wageningen University. Tekenradar.nl (Tick radar). 2019. Available at: https://www.wur.nl/en/show/Tekenradar.nl-Tick-radar.htm
- Den Broeder L, Devilee J, Van Oers H, Schuit AJ, Wagemakers A. Citizen Science for public health. Health Promot Int. 2016, 33(3):505–514. https://doi.org/10.1093/heapro/daw086

Engage with pre-existing community networks and infrastructures

Engage with pre-existing community networks and infrastructures, in particular well-connected stakeholders ('social brokers') who can link different community groups that would otherwise remain disconnected. These groups can anticipate training needs, anticipate where aid is required, and they may have networks of experienced or even pre-vetted volunteers. For example, as a group that requires legal authorisation, hunters are well organised and can be quite easily reached with information about zoonotic diseases through their various federations and clubs. Hunting schools provide information on how to take care of hunting dogs, and they also have social media groups where they keep themselves well informed and connected. Similarly, farmers are in principle easily reached via the veterinarians with whom they work on a routine basis, so the possibility exists to inform them through this channel. Pre-existing networks of disease-specific community actors can also be used for other, closely-related diseases (e.g. Lyme networks for tick-borne encephalitis), but it is important that such disease-specific community actors are informed of the different risk profiles of these closely-related diseases, particularly regarding any differences in transmission risk and disease virulence.

[ii] The 'Tick-radar' (https://www.tekenradar.nl/) enables people bitten by ticks to register their location, contact information, and, if relevant for pending research, to send in their ticks.

Options for actions

- Identify and engage with community-based networks who have valuable resources and leadership roles, particularly those who link different groups of people who would otherwise remain disconnected ('social brokers'). Promote shared leadership and ownership of processes.
- Develop agreements on how valuable community resources (e.g. transportation equipment) could be mobilised in case of a disease outbreak.
- Set up a community coordinating group that promotes joint planning for emergency preparedness, mutual aid and resource sharing, information sharing and joint education and training.
- Raise awareness among public health experts about the importance of respecting the diversity of views which could be present in the community settings regarding the potentially applicable methods and approaches to achieve the same goal.
- Document what has worked well in an AARs and ask community input regarding lessons learned.
- Recognize that some community groups may only emerge because of an emergency event, and they not see themselves as a cohesive group before this event.
- Be clear on what is expected of people and their roles. Expect changes in roles and expectations throughout the preparedness and incident process.
- Engage with the private sector as an opportunity to promote public preparedness and show them the benefit in supporting public needs.
- Maintain engagement with commercial enterprises that can contribute to emergency preparedness and response measures, and at the same time be aware of the potential risk of conflict of interest and the need to prevent or manage that. This can help make use of for-profit networks for public benefit. Not engaging with key private parties may lead to inaccurate or non-productive dissemination of information and ideas in the public realm.
- Because many healthcare workers work in both the public and private sectors, this can cause issues if information or resources are only provided to the public sector.
- Think about audience segmentation: not every network should be approached using the same language, ideas, etc.
- Be aware that emergency preparedness is not the highest priority at community level. Avoid over-reliance on community actors to prioritise emergency preparedness over what may be perceived locally as more pressing issues.

Further Information

- Center for Community Health and Development at the University of Kansas. 8. Increasing Participation and Membership. Community Tool Box. 2019. Available at: https://ctb.ku.edu/en/increasing-participation-and-membership

Set research agenda in collaboration with community partners

Conducting scientific or operational research on diseases with outbreak potential may bring about significant reductions in the burden of control measures among affected communities while also facilitating more targeted public health approaches. Decision-making regarding the desired topic of research depends on both the epidemiological and social contexts, and this varies between Member States. Some research topics may have lower epidemiological priority, yet they could bring about substantial community benefits, and vice versa. Setting the research agenda in collaboration with community partners, e.g. by including them in proposal development, has the advantage of attaining a more careful weighing of social and epidemiological priorities by seeking synergies and building on mutual understanding. Further, it facilitates the development of citizen-science initiatives.

Options for actions

- Recognise and continuously emphasise objectives of research initiatives, and throughout multi-stakeholder consultation enhance the opportunities to make these objectives shared and achievable.
- Focus on producing an agreement that could meet the underlying concerns of all stakeholders: aim to negotiate win-win compromises regarding the funding of research with medical versus societal (including civic, economic, agricultural or other) priorities.
- Focus on trust building by being transparent regarding public health political agendas or goals.
- Conduct advocacy activities and lobby with relevant funding agencies together with community-based partners. Funding for research would most likely come from national research councils or from international sources such as the EU, but possibly also from private foundations.

Further information

- Center for Community Health and Development at the University of Kansas. 14. Applying for Grants. Community Tool Box. 2019. Available at: https://ctb.ku.edu/en/applying-for-grants
- Glasbergen P. The green polder model: institutionalizing multi-stakeholder processes in strategic environmental decision-making. Eur Environ 2002;12(6):303-315.

- Harvard Law School. "Short Guide to Consensus Building: An Alternative to Robert's Rules of Order for Groups, Organizations and Ad Hoc Assemblies that Want to Operate By Consensus". Consensus Building Handbook: Chapter 1. 2019. Available at: http://web.mit.edu/publicdisputes/practice/index.html

Response phase

Coordinate access to information, protective equipment and resources for and with community partners

Ongoing provision for affected community-based actors of, for example, protective equipment and supporting information can be important for maintaining collaborative relationships, especially if the outbreak continues for an extended period. Distribute PPE or other crucial response resources (such as stool pots in the case of outbreaks of gastro-enteric disease) both centrally and through local response networks, so that they are easily accessible to community stakeholders, particularly when there are large distances involved. If regular public health staff are unavailable to respond to an outbreak, qualified replacement staff should be found to provide support, while community stakeholders are regularly informed and engaged with when relevant, to contribute with available community-based resources.

Options for actions

- Response principles should be followed: What is needed? When is it needed? Where is it needed? How is it needed? Why is it needed? Who is needed?
- Identify who in the community needs to be involved in logistical operations and provide protective equipment as appropriate.
- Whenever possible existing structures in the community should be used e.g. civic distribution structures. If possible, purchases of materials should be local.
- Develop reliable ICT support capacity when you provide technical support remotely to community-based partners.
- Good planning is needed regarding practical management and coordination issues of community-based volunteers (such as reporting, learning, safety and mobility etc).
- Award and acknowledge innovative volunteer programs, and support organised volunteers who are vetted. Poorly trained or insensitive volunteers can lead to mistrust of public institutions.
- Conduct training and simulation exercises with community based partners on the usage of, for example, PPE.

Further reading

- United Kingdom Cabinet Office. Logistic operations for emergency supplies: guidance for emergency planners. Options available to emergency planners for the coordination, prioritisation and acquisition of emergency supplies. 2009. Available at: https://www.gov.uk/government/publications/logistic-operations-for-emergency-supplies-guidance-for-emergency-planners

If using an all hazards approach, recognise the special character of infectious disease outbreaks, and act accordingly

The all-hazards approach is efficient and allows for response structures with limited staffing to deal with unexpected threats. The approach can also link community-based stakeholders, such as in the tourist sector, to a generic preparedness process. However, while there are several core principles that are always shared between the responses to infectious disease outbreaks and those of other emergency events (e.g. the need for the authorities to include community needs), there are also important differences in perception and process. For example, decisions to activate response systems may be more difficult to make during what could initially be a small outbreak in comparison with the more immediate impact of a natural disaster. Furthermore, shelters designated for use during natural disasters may not be appropriate for infectious disease outbreaks: in the latter case, there can be complications regarding cleaning and a fear of lingering contamination. Local authorities therefore need to be engaged, in advance of an outbreak, in decision-making regarding the most suitable places for disease outbreak control quarantine shelters.

Options for actions

- Ensure that the following points are addressed in all-hazard plans that include the potential of an outbreak of a pathogen with the potential for propagation:
  - Screening, surveillance, and contact tracing (of exposed individuals), if necessary.
  - Controlled hospital access
  - Prevention strategies, e.g.:
    - Isolation and cohorting (putting people with the same symptoms together)
    - Personal protective equipment coordination, training and usage

    - Vaccination and chemoprophylaxis, including deployment plans to treat multiple people
    - Modification of environmental controls.
- Ensure that key community-based decision-makers and response leaders are trained in basic processes of outbreak control.

Further reading:

- Centers for Disease Control and Prevention. All-Hazards Preparedness Guide. 2013. Available at: https://www.cdc.gov/cpr/documents/AHPG_FINAL_March_2013.pdf
- Elizabeth Lee Daugherty, Abigail L. Carlson, Trish M. Perl, Planning for the Inevitable: Preparing for Epidemic and Pandemic Respiratory Illness in the Shadow of H1N1 Influenza, Clinical Infectious Diseases, Volume 50, Issue 8, 15 April 2010, Pages 1145–1154, https://doi.org/10.1086/651272.
- ECDC. Joint European Centre for Disease Prevention and Control and WHO Regional Office for Europe Consultation on pandemic and all hazard preparedness. 20–21 November 2013 Bratislava, Slovakia. Available at: https://ecdc.europa.eu/sites/portal/files/media/en/publications/Publications/Joint-ECDC-WHO-Europe-Consultation-on-pandemic-and-all-hazard-preparedness-meeting-report.pdf

Facilitate discussions on possible compensation of community-level financial losses

Advocating for, and facilitating the development of clear operational protocols to use dedicated state compensation funds aimed at covering expenses incurred by communities affected by infectious disease outbreaks could facilitate involvement of community stakeholders in responding to infectious disease outbreaks, when there are options for receiving compensations for possible losses that could occur during response and recovery actions. Overall, such practices could have significant and positive public health benefits. While funds for response and recovery may be available to regional authorities, outbreaks can be costly to individuals and local companies in affected communities, who might have to invest significant financial, material and human resources to deal with the outbreak itself or the aftermath. Examples of these costs can be;

- covering the fees of professional cleaning services to sanitise shelter facilities utilised during an outbreak
- compensation for material losses or losses from clients, students, staff or patients
- compensation for the wages or jobs lost by those who had to suspend professional activities to care for family members or socially vulnerable members of the community while sick.

Such financial burdens can severely affect community organisations, groups, households and individuals, and they can also undermine future adherence to or engagement in response activities.

Options for actions

- Share knowledge about compensation schemes to encourage people to report disease, instead of hiding cases in order to try to avoid financial difficulties.
- Clarify options, including statements about the provisions and support services available for those affected by restrictive measures, and facilitate public discussions about levels of compensation.
- Recognise that quarantine measures can lead to loss of income and employment, putting livelihoods at stake.
- Ensure public awareness of the rationale, benefits, and consequences of restrictive measures that could have financial implications for affected communities.
- Consider the implementation of measures to protect against stigmatisation and to safeguard the privacy of those involved.
- Facilitate and advocate for the inclusion of clauses in relevant legislation, which detail compensation of financial losses due to restrictive measures.
- Develop a system of reporting and decision-making for immediate decisions on compensation in cases where a high level of compensation is expected (depending on the given mandates of public health authorities in specific legal provisions in a country).

Further reading

- Cheonsoo Kim. Legal Issues in Quarantine and Isolation for Control of Emerging Infectious Diseases. J Prev Med Public Health 2016; 49(1): 1-17. https://doi.org/10.3961/jpmph.16.009
- Smith KM, Machalaba CC, Seifman R, Feferholtz Y, Karesh WB. Infectious disease and economics: The case for considering multi-sectoral impacts. One Health. 2019;7:100080. Published 2019 Jan 9. https://doi:10.1016/j.onehlt.2018.100080

Recovery phase

Integrate and document community engagement in evaluation processes

Participation of community-based partners in the monitoring and evaluation of preparedness and response processes motivates consideration of societal and community-level impact that may otherwise be left unrecognised. Ongoing efforts should be made to ensure that the lessons learned from public health events are documented through AARs, fed back into preparedness plans, and archived in an accessible way for both institutional and community-level stakeholders. Part of this process should include specific references to community engagement activities that were undertaken during outbreaks, such as details on meetings, activities relating to the collection and processing of biological samples, and the provision of information to community-based actors. Integrate such knowledge on effective community engagement into general disease outbreak guidelines. Such activities would promote formal recognition of the importance of community-based partners in response activities. In addition, a synthesis of the recommendations from previous outbreak reports, along with a broad dissemination process would help to ensure that the lessons learned from previous experiences are remembered, referenced and acted upon. Finally, community-based actors can also be included in the development of indicators to monitor the entire process (pre-incident, incident, post-incident).

Options for actions

- Start the evaluation in the field with a 'hot wash', during which responders (e.g. healthcare personnel, ambulance, fire and police, Red Cross and other relevant community-based stake holders) are systematically asked, directly after the incident, what they thought of the response.
- Conduct AARs, ideally within three months after an event is formally declared over.
- Archive AARs and make them easily accessible to appropriate stakeholders and include media analysis.
- Ensure the inclusion of a diversity of opinions during the evaluation or AAR, going beyond the health sector at all levels, such as municipality or local government authorities, community groups or other beneficiaries, representatives of academia, national and international partners or representatives of the private sector. Additionally, include representatives of other involved sectors such as the Ministries of Environment, Agriculture or Civil Protection.
- Support the development of community-level monitoring systems that enable communities to monitor their own action plans and the work of public health authorities and other institutions.
- Develop accessible indicators in collaboration with community stakeholders, and ensure adequate training and capacity building. The indicators should strengthen collaboration and preparedness and response capacity. The most useful indicators may be identified using SMART criteria[iii].
- Consider requesting the assistance of local academic or research institutions to undertake external evaluations.
- Facilitate the storage, collation and sharing of good community engagement practices.
- Integrate lessons learned into preparedness planning and when relevant into national disease guidelines

Further reading

- Guidance for After Action Review (AAR). Geneva, Switzerland: World Health Organization; 2018. Licence: CC BY-NC-SA 3.0 IGO. Available at: http://www.euro.who.int/en/health-topics/emergencies/international-health-regulations/monitoring-and-evaluation/after-action-review/guidance-for-after-action-review-2018
- Fact sheet - IHR Tools for monitoring and evaluation: After action review. 2018. Available at: http://www.euro.who.int/en/health-topics/emergencies/international-health-regulations/monitoring-and-evaluation/after-action-review/fact-sheet-ihr-tools-for-monitoring-and-evaluation-after-action-review-aar

iii SMART: Specific: Is the indicator specific enough to measure progress towards the results? Measurable: Is the indicator a reliable and clear measure of results? Attainable: Are the results in which the indicator seeks to chart progress realistic? Relevant: Is the indicator relevant to the intended outputs and outcomes? Time bound: Are data available at a reasonable cost and effort?

Promote community debriefing, dialogue and a culture of shared learning

The post-event period is a window of opportunity that facilitates the development of relationships between people, and which can encourage formation of local volunteer groups. Post-event debriefs and feedback sessions, including AARs, with community-level stakeholders are essential to develop trust for future events. At the same time, such activities support system-wide learning that feeds into the next round of the preparedness planning cycle. Debriefing sessions should motivate dialogue about what happened and what was done, verification of observed community impacts, and possible improvements for next time, without judgments or taking criticisms too personally. Feedback regarding community involvement and participation is essential to community engagement activities and is an inherent part of the learning process.

Options for actions

- Promote a learning culture within public health institutions and the community to benefit future response capacity.
- Find common ground with the parties involved by listening to each other's arguments to understand perspectives, needs, expectations, or solutions. Facilitate a common vision, understanding, or solution to a specific issue of concern to facilitate future preparedness and response.
- Display open-minded attitudes and a willingness to review both effective measures and shortfalls in actions and accept change.
- Try to build a 'strategy of no regrets' whereby it is accepted that the decisions made may not have been the best, but they should be accepted for what they were, and they should be learned from and improved for the future.
- Carefully manage expectations of feedback sessions. There will have to be room for complaints and grievances. Solicit the support of technical experts with experience in facilitating communication, mediation or conflict resolution to lead such process as neutral parties.
- Motivate participants to agree on final conclusions, ensuring everyone's buy in.
- Conduct debriefings at different organisational levels, including a post-event debriefing with healthcare workers.
- Disseminate findings from dialogue and knowledge gained to all partners.

Further reading

- MENA Common Ground Institute (CGI). Community Dialogue Design Manual. 2016. Available at: https://www.sfcg.org/wp-content/uploads/2017/07/CGI-Anglais-interactive.pdf
- Joint Emergency Services Interoperability Principles. Joint Organisational Learning Guidance. 2017. Available at: https://www.jesip.org.uk/uploads/media/pdf/JOL_Guidance_October_2017.pdf
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Implementation of the guidance

This guidance can be useful in EU/EEA Member States where public health authorities would like to develop or update their community engagement strategies. A checklist for the most significant issues covered is provided in Table 4. When implementing this guidance all the presented issues need to be considered, but implementation requires prioritisation and adaptation according to country-specific socio-cultural, epidemiological and political contexts. Beyond the state level, it may be worth considering disseminating this document, with the key points translated into the local language as appropriate, to regional and local level stakeholders for regional adaptation as necessary. In some countries, any community engagement strategy may need legal approval before it can be considered in preparedness planning or response. Informal steps can be made in the meantime, but advocacy and lobbying are prerequisites for successful implementation.

Community engagement is a specialty area that requires skilled practitioners. A dedicated engagement officer or team could be given responsibility to further support implementation. At the same time, it is important to keep in mind that community engagement is not just for the engagement team itself, but as a core public health function it should be mainstreamed throughout many processes. Such mainstreaming includes advocating for it as a core function and educating medical professionals to be receptive and empathetic toward community engagement as a vital public health function that need their understanding and support (such educational programmes or elements of them might already be present in medical studies curricula).

Finally, implementation is not necessarily strictly government led. There are independent community-based partners with professionalised community engagement capacities. An obvious example is the Red Cross Red Crescent's comprehensive community engagement and accountability strategy [14]. Smaller initiatives also need to be recognised. For example, the Dutch Tick Radar initiative is an independently-led tool that has its own website and communication campaign. Implementation strategies in such contexts are best seen as synergistic to public health authorities' implementation of community engagement.

Successful community engagement strategies seek to build upon local initiatives, and if these are absent, they should strive for early inclusion of relevant community partners. Although community participation can be unstructured, lengthy, and sometimes even oppositional, shared ownership of implementation processes with community partners will most likely lead to more sustainable and effective outcomes in the long term than without them.

Conclusion

When seen as partners, community actors can provide crucial resources, support networks and knowledge about local perceptions and contexts to outbreak preparedness and response programming. Because community partners have a stake on the outcome of these programs, they want to be heard. Yet they also heavily rely on public health expert advice during times of public health emergencies. This points to one of the more difficult elements of community engagement: the careful balancing of expert advice with the democratic inclusion of community voices. For increasing the efficiency of response as well as from a human rights perspective it is important that community groups, particularly those vulnerable to an outbreak (for a variety of reasons, e.g. hard-to-reach, socially marginalised, susceptible, etc.), get attention to ensure that their voices are heard and responded to, and that they gain information in the most impactful way.

There is no 'one-fits-all' way of going about community engagement. However, there is broad agreement about the fundamental principles for community engagement across various frameworks and guidance documents [15]. At its core, community engagement starts with considering what the desired level of community engagement (outreach – consult – involve – collaborate – shared leadership) may be [7]. Community engagement should be an ongoing process – an attitude – in which trust-building is the driving mechanism. Development of trust is the crucial precursor for effective engagement and collaboration during a public health emergency. To achieve trust, areas of priority include mapping and integrating community needs and desires, early inclusion of community actors in the process, building on existing community structures and networks, and transparency regarding public health emergency preparedness and response objectives and desired community participation levels.

Table 1. Summary of the 14 guidance points and a checklist for the most significant issues covered

Phase	Guidance	Checklist
All three	1. Recognise the community as a partner	Is there enough willingness to consider community input and roles? Is there sensitive and community-appropriate outreach? Are community partners empowered to contribute? Are there feedback loops on successes of community engagement?
	2. Develop understanding of community perceptions	What is in place to 'listen' to community attitudes and beliefs? Is it clear what priorities need to be considered from the community's point of view? Is misinformation directly and regularly addressed using credible spokespersons?
	3. Optimise communications with at-risk communities	Are there guidance documents developed in collaboration with civil society for community partners and at-risk groups? Are messages segmented depending on the audience's health literacy, risk perceptions, and cultural understandings?
	4. Invest in a trusted spokesperson and long-term media relations	It there a trusted and consistent spokesperson, as well as a backup? Are key media contacts continuously engaged, updated and trained?
Anticipation	5. Map stakeholders and integrate them in preparedness planning.	Have community-based partners been considered for inclusion in risk ranking exercises? Have stakeholders been identified, differentiated and categorised and their relationships, resources, knowledge gaps and training needs analysed? Is their regular updating of stakeholder map? Has guidance on contact tracing and vulnerable/hard-to-reach risk groups been developed collaboratively? Have community-based partners been integrated early in preparedness planning?
	6. Develop and accessible and inclusive preparedness and response training program	Are community-based partners included in training development, simulation exercises and trainings? Do simulation exercises and trainings include community engagement components? Are guidance documents (such as on the use of infection prevention and control measures) easily accessible in the public domain?
	7. Cultivate relationships with communities engaged in disease surveillance	Are community-based groups engaged in surveillance collaborating through citizen science or other participatory projects? Are those contributing data to surveillance receiving feedback on how their contributions are used? How are data shared?
	8. Engage with pre-existing community networks and infrastructures	What existing community networks and infrastructures can be engaged in? What resources can these networks mobilise? Are there specific groups that connect many others that need to be included? Are there closely related community-based disease networks that can be engaged?
	9. Set research agenda in collaboration with community partners	Are there attempts to negotiate funding of research on societal issues (civic, economic, agricultural or other)?
Response	10. Coordinate distribution of information, protective equipment and other resources for and with community-partners	Do community-based partners have access to protective gear and other crucial response resources, as appropriate? Are surge and/or backup personnel arranged and updated regarding community-based resources and key stakeholders?
	11. If using an all hazards approach, recognize the special character of infectious disease outbreaks, and act accordingly	What special provisions are in place to deal with the contagious character of health emergencies? Are key staff of NGOs and other community actors trained on basic outbreak processes?
	12. Facilitate compensation of community-level financial losses	Are operational protocols in place to use designated state compensation funds aimed at covering expenses incurred by communities affected by infectious disease outbreaks?
Recovery	13. Integrate and document community engagement in evaluations processes	Are operational protocols in place to use designated state compensation funds aimed at covering expenses incurred by communities affected by infectious disease outbreaks?
	14. Promoting community debriefing, dialogue and a culture of shared learning	Are community-based partners included in hot-washes, After Action Reviews, and other evaluation mechanisms, or the monitoring and evaluation of processes? Are the lessons learned from public health events documented and archived in an accessible way?

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Annex 1. Methodological considerations

Sources of evidence

Literature review

Before the start of the case study project, a literature review was conducted in 2016 that identified enablers and barriers to community and institutional synergies in emergency preparedness [5, 11]. Searches were undertaken across bibliographic databases and grey literature sources. There were no restrictions on country or study type, thereby incorporating a comprehensive range of contexts and findings. The literature identified was qualitative in nature. Systematic methods were used to pragmatically identify the most relevant literature in this area, and the search process was documented to ensure transparency. The review used different methods of document identification and retrieval to ensure that key references were included. From a database search, 581 articles were identified, and a further 15 articles were identified through grey literature and a call for evidence from ECDC. After screening, a total of 35 documents remained, describing factors influencing community and institution synergies in emergency preparedness. A qualitative, 'best fit' framework approach using a pre-existing framework of the National Institute of Health and Care Excellence (NICE) [16] was used to analyse the literature, whereby themes were added and adapted as the analysis progressed. The review followed PRISMA guidelines.

Case studies

Case studies were conducted in four EU/EEA countries in 2017 and 2018 in Spain, the Netherlands, Iceland and Ireland. These countries were selected in agreement with ECDC and the authorities in the countries concerned. Spain and the Netherlands were selected for inclusion in the case study project based on emerging tick-borne disease incidents that occurred in 2016. Work in Spain focused around two autochthonous cases of infection with Crimean-Congo haemorrhagic fever (CCHF) virus that emerged in the Autonomous Community of Castilla y León in August 2016 [17, 18]. In the Netherlands the focus was on tick-borne encephalitis (TBE), with the first two endemic cases in the country appearing in July 2016 [18, 19]. These TBE cases were considered within the broader context of a widespread and increasing incidence of Lyme borreliosis in the Netherlands, and the associated networks that have evolved as a result.

Iceland and Ireland were selected for inclusion based on outbreaks of acute gastroenteritis. In Iceland, investigations focused on an outbreak of norovirus infection that emerged during an international scouting event in the south of the country in August 2017. In Ireland, our case study examined verocytotoxin-producing *Escherichia coli* (VTEC) as a wider public health issue, but also with a focus on a single outbreak that occurred in a child care facility in mid-2018 [20, 21].

Table 2. Number of respondents in the four participating countries, by type of data collection

	Focus groups (number of participants)	Interviews	Total respondents
Spain	3 (15)	13	28
Netherlands	2 (10)	21	31
Iceland	4 (23)	15	38
Ireland	3 (25)	15	40
TOTAL	**12 (73)**	**64**	**137**

All the case studies were based on qualitative sources of evidence, including: document and media review; interviews and focus group discussions with community representatives and with a range of technical experts working at national and regional level; and a stakeholder mapping exercise (see Appendix 2 for details). Potential interview and focus group discussion participant categories were discussed and agreed in close collaboration with ECDC and the respective country counterparts. Respondents were selected at national, regional and community levels. Each country visit took place over one full working week, and the interviews/FGDs were conducted by experienced social scientists. Table 1 shows the number of respondents who took part in interviews and focus groups in each participating country. Written informed consent was obtained from all interviewees and focus group participants.

The data were subjected to grounded, thematic analysis, for which the themes were based on a theoretical preparedness cycle that includes the pre-incident, incident, and post-incident phases [9]. Finally, the empirical findings were compared to the outcomes of the literature review in order to check their alignment with previous research. All the major categories found in the literature were also reflected in the findings.

Following the well-established quality criteria of Lincoln and Guba for qualitative research [12], the trustworthiness of the empirical findings from the case studies was deemed sufficient for evidence-based guideline development[iv]. *Credibility* (accurate understanding of social life world) of the results was increased due to the identification of elements most relevant to the problem or issue pursued through persistent observation, triangulation of findings through the different data collection methods, a collaborative research approach including local representatives, end of fieldwork peer debriefing, and an extensive review process verifying findings, including with representatives from whom data were originally obtained. *Transferability* of the findings was supported by detailed descriptions of the original finding for each case study, allowing team-based identification of results that occurred across context. Further, *dependability* was enhanced by including the same core team across the design, implementation and review of all case studies, having outside researchers examine the study methodology and products to evaluate accuracy, and extensive documentation and transparency of the methodology used. Finally, with respect to *confirmability*, an extensive audit trial exists in country-specific case studies, illustrating research steps taken. Furthermore, because experienced qualitative researches led the fieldwork, and analysis was conducted with input from local representatives, a reflexive research process was maintained.

Expert consultation

Based on the empirical findings and the results of the literature review, a draft version of this guidance document was critically reviewed and its content validated at an Expert Consultation held at the ECDC offices in Stockholm on March 27/28 2019. The draft guidance that informed the experts' judgments for recommendations systematically and consistently described empirical findings and linked these findings to specific recommendations. Participants at this meeting included 20 international community engagement actors, technical experts, and ECDC stakeholders, including the National Focal Points for Preparedness and Response from the four countries that participated in the case studies. The Consultation collected feedback on the content and preferred format of the guidance document, including concerning the meaning of community engagement, what has worked successfully in different contexts and what has not, the identification of enabling factors and barriers, as well as issues of layout, format and structure. In the final guidance development, efforts were made to distinguish expert opinion from expert evidence [13], the latter given priority. No new evidence was introduced after relevant documents have been circulated, commented on by panel members, and finalised. Further, none of the participants had any secondary, financial interests, such as research funding, consulting income, or stock ownership.

Strengths and weaknesses

The key strength of this guidance is that its development has been based on empirical case studies in a European context that built upon a preliminary model of community engagement derived from a comprehensive literature review [5, 11]. The original framework that was derived from the literature review was organised around the themes of context, infrastructure and process. **Context** refers to the needs for a supportive, collaborative relationship from the outset, including the nurturing of quality relationships and the trust needed for success and rapid mobilisation. **Infrastructure** refers to identifying what the community can achieve independently, as well as areas that could be supported by external agencies. Finally, **process** refers to the need for a flexible approach to community preparedness, since communities are dynamic, complex entities and therefore no uniform approach will fit every context. This context-infrastructure-process framework informed the content of the questions asked during the case studies.

At first sight a weakness of the guidance is the relatively low number of disease categories – emerging tick-borne diseases and acute gastroenteritis – that were used as basis for the case studies in the four European countries. Moreover, all case studies dealt with relatively small events. However, when the case studies are mapped onto the socially relevant category of level of expectation (expected versus surprising) and the disease category of severity of impact (mild – severe), as shown in Table 2, a broader typology emerges that shows how the case studies actually sampled a wide variety of disease outbreak experiences. The typology is based on the extent to which the event was expected by involved stakeholders relative to the biosafety classification of the disease, the latter according to Directive 2000/54/EC of the European Parliamentv.

Table 3. Typology of outbreak events studied.

iv Lincoln & Guba make a case that trustworthiness of a qualitative research study is important to evaluating its worth. Trustworthiness involves establishing: Credibility - confidence in the 'truth' of the findings, Transferability - showing that the findings have applicability in other contexts, Dependability - showing that the findings are consistent and could be repeated, Confirmability - a degree of neutrality or the extent to which the findings of a study are shaped by the respondents and not researcher bias, motivation, or interest.

v European Parliament. Directive 2000/54/EC of the European Parliament and of the Council of 18 September 2000 on the protection of workers from risks related to exposure to biological agents at work (seventh individual directive within the meaning of Article 16(1) of Directive 89/391/EEC). 2000;L 262,17/10/2000(Official Journal L 262 , 17/10/2000 P. 0021 - 0045).

	Biosafety classification		
	II	**III**	**IV**
Expected		VTEC (Ireland)	
Surprising	Norovirus (Iceland)	TBE (Netherlands)	CCHF (Spain)

This typology helps illustrate how, when taken together, the case studies provide an empirical basis for broader generalisation. It suggests that the core principles identified would likely also be relevant to many other disease categories, including larger events that fall within this typology. This was further confirmed when we found a high level of agreement between the lessons learned from the literature review phase and the findings from the empirical case studies.

In spite of these overall strengths of the guidance points presented, it is important to note that some additional points raised during the consultation process were not integrated because no empirical data were available to further support them. These included issues of community engagement related to cross-border and internal migration as well as psychosocial care, including stigmatisation within communities [22]. Aside from this, however, we believe that the guidance points constitute a valid and viable approach to developing community engagement activities within the EU/EEA.

Annex 2. Stakeholder analysis: example from the Netherlands

In the Netherlands, after scale-up of the response during the TBE incident, the National Institute for Public Health and the Environment (RIVM) conducted a stakeholder analysis that identified both information needed by stakeholders from the official outbreak coordination group, as well as what the stakeholders could offer RIVM. The coordination team wanted help from all stakeholders in collecting information about how health communication messages had been reaching at-risk groups, while at the same supporting the same stakeholders by providing more ready-made information.

For medical care stakeholders, close collaboration with professional associations was an effective way of reaching risk groups, while simultaneously raising awareness of TBE among medical doctors. Dissemination of information and updates regarding ongoing studies concerned with TBE were supportive instruments for this stakeholder group.

With respect to government and media institutions, emphasis was placed on accurate, audience-specific, up-to-date information to avoid both unnecessary public unrest and the spread of incorrect information.

Finally, the large number of stakeholders belonging to knowledge institutions and other associations acted as key partners for supporting ongoing research studies and dissemination of information to patients. If studies showed that certain population(s) were more at risk of TBE, more local parties could be included in direct information outreach. The RIVM singled out the Association of Forest and Nature Owners as an especially relevant partner, as they are an umbrella organisation including various green partners.

Table 4. Example of needs as expressed by different take holders

Stakeholder	What the official outbreak coordination group needs from stakeholders	What stakeholders need from the official outbreak coordination group
Risk groups		
Forestry, green and fieldworkers*	Percentage of people with tick bites and how many of these TBE to provide correct measures and advise Information about behaviour and basic knowledge about prevention for improvement Information collection regarding actual use of prevention measures (STIGAS and Forestry Service)	Practical prevention guide Practical information about when to consult a general practitioner Vaccination advice Risk assessment in relation to proportionality of measure
Medical care providers/medical stakeholders		
Municipal Health Services	Information about patients (surveys/signals) More public communication, both active and passive Advise municipalities about TBE risks	Offering surveys for patients Ready-to-go public communication messages Creating more alertness
General Practitioners	Disseminate information to risk groups Alertness among people without frightening them	Ready-to-go information on disease and diagnosis Creating more alertness
Government/politicians/media		
(Social) media	Provision of proportionally correct information to target audience	Ready-made public information Practical information on when to consult a physician
Knowledge institutes/associations		
Dutch Association of Lyme Patients	Signals about personal perceptions, and frequently asked questions; Provision of correct information to patients;	Well supported information (specialized information relative to the general public).
Royal Dutch Hunting Association, farmers and property owners	Collaboration in research; Building and keeping trust.	Early signalling to be able to anticipate public health emergencies; Ready-made information; Applicable instructions for research sampling; Feedback on results.

Source: [23]
** Multiple nature or landscape management organisations: Forestry service, nature conservation organisation (Natuurmonumenten), Federation of private properties etc.*

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