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# THE USE OF PARTICIPATORY METHODS IN THE EVALUATION OF HEALTH SURVEILLANCE SYSTEMS

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**KEYWORDS:** Epidemiological surveillance • Evaluation • Acceptability • Participatory approaches

**ABSTRACT**

Surveillance systems rely on a network of stakeholders who share information. Socioeconomics factors have an influence on their decision to share or not the information within the system. Those factors are rarely taken into consideration, especially in the evaluation of surveillance systems.

Participatory approaches derived from social sciences have proven useful to take these factors into account and have been adapted over the past 15 years to the context of health surveillance system evaluation. The "AccePT" (Acceptability Participatory Toolkit) method based on participatory approaches has been developed to assess the acceptability of surveillance systems. The method takes into consideration the adequacy of objectives and operation in the system for the stakeholders, the satisfaction of their roles, and their level of trust within the system. This approach allows stakeholders to freely discuss or think about how they experience working or not working with other partners, and to provide context-based recommendations taking into consideration their perceptions, expectations, and needs.

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## 8.1 Introduction

Surveillance systems in animal health were established during the twentieth century following the increase in international trade in live animals and animal products that contributed to the spread of diseases between countries. These complex strategies are put in place to monitor the progress of diseases and to facilitate their control [1]. They respond to public health issues, by protecting human populations from zoonotic risks; to economic issues, by maintaining the national herd and access to international trade; and also to biodiversity-related issues by ensuring the protection of threatened species. Animal health surveillance systems are decision support tools defined by "the systematic and continuous operations of collection, compilation and analysis of animal health information, as well as their dissemination within a timeframe compatible with the implementation of necessary measures" [1]. The information produced by surveillance systems supports decisions on what measures are appropriate, including prevention, control, and research. Animal health surveillance is carried out by a variety of stakeholders, involved at different scales, organized as networks of actors. Information such as epidemiological data and decisions on disease control measures and animal health management must flow in a multidirectional manner in these networks. Dissemination of information is thus an essential element that determines the motivation of a large number of surveillance actors [2].

Surveillance systems have certain limitations that influence their performance in accurately describing the epidemiological situation of a given population. These limitations are related to underreporting, reporting delays, lack of data management, limited representativeness, or imposed budgetary constraints [3]. It is fundamental to evaluate these systems regularly and appropriately to ensure their performance, but also to determine whether the relevant stakeholders are fully engaged and the resources provided are used optimally. Current evaluation approaches are generally not very flexible and do not always consider the context in which the surveillance system is implemented [4-7]. The socioeconomic aspects of surveillance are also poorly considered despite their impact on surveillance performance [8, 9].

## 8.2 Importance of Sociological and Economic Factors in the Surveillance System Performances

The proper functioning of surveillance systems depends on technical and economic operating constraints as well as social issues generated by the networks of actors involved [10, 11]. The design of more effective and efficient surveillance systems, as well as their evaluation, requires the application of innovative methods and tools accounting for the perceptions, expectations, and needs of the different actors.

To be functional, epidemiological surveillance must be based on a network of actors who share common (or at least compatible) interests, derive mutual benefit from the network operations, and have a common understanding of the circulating information. In other words, these actors must share a common perception of the disease to be monitored and give the same definition of what is a reportable case. Social factors can have important consequences on the validity and the performance of the surveillance strategies, in particular with regard to the problems of stigmatization of individuals or of a social group. It is therefore necessary to be inclusive of the multiple actors—breeders, veterinarians, consumers, traders—who contribute, more or less autonomously, in the management of risks and crisis situations associated with the emergence of diseases. Therefore, the inclusion of a social dimension not only aims to identify the human

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factors that promote the circulation of health information, but also supports the definition of the modalities of risk co-management.

Participatory approaches derived from social sciences have proven useful over the past 15 years to integrate social factors into the evaluation of health surveillance system [6, 7, 12-15]).

## 8.3 Advantages of Using Participatory Approaches in the Evaluation Process

Participatory approaches have been initiated in Southern countries with the aim of responding to development issues facing local communities. After being applied to many areas such as natural resource management or agriculture, participatory approaches began to be applied to veterinary epidemiology in the 1980s [16, 17]. Participatory epidemiology (PE) is often used for animal health surveillance in developing countries, where the human and financial resources of veterinary services are limited. This method essentially makes it possible to collect qualitative or semiquantitative data on animal health and disease occurrence. It has been applied in animal disease surveillance in Africa (notably in the rinderpest eradication program) and Asia [18]. PE could be defined as social sciences applied to health data collection and disease control. It requires interactions between stakeholders and focuses on the understanding of local priorities [12].

Based on local and traditional knowledge, these methods actively involve grass-roots stakeholders, mainly herders (key actors in disease reporting) to collect infor-mation on the health situation [17]. They can be applied in addition to conventional surveillance methods in the identification of field clinical cases that are not detected by passive surveillance systems if the cases can be confirmed by specific biological tests [19-21]. Their main advantages are to increase ownership of the stakeholders in the surveillance system and to increase sustainability of surveillance by relying on formal and informal stakeholder networks [12].

We have applied these approaches to the evaluation of surveillance systems in animal health in South East Asia and Europe (cf. case studies) [6, 7, 14, 22, 23]. Evaluation processes have been used in many areas, including program, performance, and policies evaluations. Evaluators often find themselves faced with the resistance of actors to engage in evaluation processes, which is perceived as a form of judgment [24, 25]. In order to improve the design and implementation of evaluations, but also to optimize the use of results in decision-making, it is important to pay particular attention to stakeholders and to involve them early on in the process [26]. We therefore propose to shift from a top-down approach, in which no consultation processes are used, to more participatory approaches. Participatory approaches can provide the necessary flexibility for evaluation in different context and allow the collection of complementary and essential information on the socioeconomic aspects of surveillance. This process should enable discussion, communication, negotiation, knowledge sharing, and should provide a strong basis for the common identification of socially acceptable solutions. Participatory evaluation leads to stakeholder empowerment in the process, which could improve the sustainability of surveillance systems.

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# 8.4 Application of Participatory Methods to Surveillance System Evaluation

## 8.4.1 THE ACCEPT METHOD TO ASSESS SURVEILLANCE SYSTEM ACCEPTABILITY

Calba et al. [27] have developed a method to estimate the acceptability of animal health surveillance systems based on the use of participatory approaches: the Acceptability Participatory Toolkit (AccePT). This method combines a series of participatory tools used with stakeholders to measure (i) their perception of system objectives, (ii) their perception of the monitoring process (their role, constraints, and relationships with other actors in the system), and finally (iii) their confidence in the system; three essential elements for the acceptance of the surveillance system by its actors [3, 7, 14].

This method was applied to a pilot study on surveillance of porcine pests in Corsica [6, 7] with the aim of determining the applicability of participatory processes in a developed country context with various actors and to test the methodology in the field. It was subsequently applied to the surveillance of bovine tuberculosis in Belgium [14] and to evaluate the acceptability of a multistakeholder wildlife health surveillance network in Cambodia [23].

### 8.4.1.1 DEFINITION OF THE ACCEPTABILITY OF A SURVEILLANCE SYSTEM

Acceptability refers to the willingness of individuals and organizations to participate in surveillance, as well as the extent of involvement of each of these users [28]. This attribute of evaluation is considered to be one of the main qualities of surveillance by the United States Center for Diseases Control and Prevention (CDC) [29].

Health surveillance systems are composed of a broad range of stakeholders, and they all have different responsibilities toward, different perceptions of, and different ways of thinking about the surveillance system. Therefore, one of the biggest challenges within the system is to bring every one of them to a position of mutual interest. Stakeholders' willingness to support the system, their satisfaction of the operation, and of their own roles are strong pillars to an effective surveillance system [23].

In order to limit underreporting, it is crucial to determine the stakeholders' perceptions and expectations regarding surveillance, and thus their level of acceptability. This attribute is all the more important as it can influence the performance of the surveillance system, for example, by influencing the sensitivity and responsiveness of the system [15].

Despite this, this attribute is not always measured or when it is, the methods used (e.g., structured questionnaires) do not always make it possible to highlight the points of view and expectations of the actors [3].

The different elements considered in estimating the acceptability of surveillance systems as well as the questions and participatory tools to document them are detailed in Table 8.1. This approach allows participants to consider and discuss their experience working with other stakeholders, identify potential issues doing so, and possible solutions.

### 8.4.1.2 GENERAL METHOD FLOW

The AccePT method consists of individual face-to-face interviews or focus groups of 5-10 participants. Focus groups are preferred because they allow participants to share their experiences and compare their points of

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view. Their strength lies in the establishment of a debate until a consensus is reached. Any type of stakeholder involved in the surveillance system targeted by the evaluation should be involved in this participatory process (e.g., breeders, veterinarians, laboratories, government departments, etc.). The selection of participants will depend on the willingness of the actors to take part in the study. Moreover, participants should not combine actors with different experience of the system in one focus group discussion where they are required to produce only one combined ranking even though they play in the same position. Best to separate them into groups with the same experience and knowledge of the surveillance system, that way will help to maintain the discussion and experience sharing without compromising the assessment goal. We should avoid situation where actors are required to discuss or rank stakeholders that they have not worked with. Some participants that hold high position in the government might struggle to provide direct response to the interview. In this case, interviewer needs to be mindful of these biases and be prepared to handle the interview at the best of his possibility. It is also essential to obtain approval from the local ethics committee and obtain informed consent from each participant before conducting interviews. In addition to representing large categories of stakeholders, caution should be exercised in the selection process to not inadvertently exclude important groups of individuals in a way that would bias the outcomes (e.g., different ethnic groups, size of the breeding operation, the membership to hunter association, etc.). Indeed, the perception of the surveillance system may vary depending on these elements. The interviews are set up following several steps that are the same for individual interviews and focus groups. Each interview begins with an introduction of the participants, the facilitator, and evaluation team, the project and its objectives, as well as the outline of the interview. Following this introduction, the various tools are used, and results are summarized at the end of the meeting. Finally, the participants are thanked and informed of what feedback they will receive following the result analysis.

***Table 8.1*** *Considerations for measuring the acceptability of a surveillance system, associated participatory questions, and tools*

| Elements | Question | Participatory tools |
|---|---|---|
| *Objective* | Is the objective of the surveillance system in line with the objective expected by the actors of the device? | Flowchart diagram |
| *Process* | | |
| Role of each actor | Are stakeholders satisfied with their duty within the surveillance system? | Flowchart diagram |
| Consequences of information flow | Are stakeholders satisfied with the consequences of information flows? | Impact diagram associated with proportional piling |
| Relations between actors | Are actors satisfied with the relationships they have with other actors involved in the system? | Relationship diagram associated with rating smileys |
| *Trust* | | |
| In the system | Do the actors trust the surveillance system to achieve the objectives? | Flowchart diagram associated with proportional piling |
| In the other actors | Do actors trust other actors involved in the scheme to fulfill their role in surveillance? | Flowchart diagram associated with proportional piling |

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### 8.4.1.3 PRESENTATION OF THE TOOLS RELATIONAL DIAGRAMS AND RATING SMILEYS

Relationship diagrams are used to identify the professional network of participants and to define the interactions between them. With this tool, participants are introduced to the evaluation process and asked to qualify their professional relationship with other actors on a 3-point scale: insufficient, sufficient, or more than necessary relationship. The activity does not focus exclusively on relationships within the surveillance network, but extends to other professional relationships participants may have outside the network (Fig. 8.1). Once the chart has been developed, the next step is to determine the level of participant satisfaction with the relationships with each member of their professional network. Colored game tokens, with graded smiley face on one side, are used on the diagram, representing five levels of satisfaction: very unsatisfactory, unsatisfactory, moderately satisfactory, satisfactory, very satisfactory. The goal is to place one and only one smiley per actor or organization identified (Fig. 8.1).

**Flow Diagrams Associated with Proportional Piling**

Flow diagrams are used to determine participants' perceptions of the flow of infor-mation within the surveillance system, for instance, the reporting of a suspected case of the disease under surveillance. This exercise facilitates the identification of the different paths that this information can take, whether official or informal. Once participants have completed the diagram, the proportional piling method is used to estimate their level of trust. This tool is applied in two stages: the first stage provides an estimate of the trust participants have in the surveillance system, the second stage assesses trust between actors of the network. Participants are asked to allocate 100 game tokens in two piles in order to highlight the trust they place in the functioning of the whole surveillance (the higher the number of tokens, the greater the trust). Then, in a second step, to distribute these tokens among the various actors identified, according to the same principle (Fig. 8.2).

**Impact Diagrams Associated with Proportional Piling**

Impact diagrams are used to determine participants' perceptions of the positive and negative impacts of a particular event and to document the consequences that participants directly experience. In our case, the specific event is a suspicion of the disease under surveillance.

***Fig. 8.1*** *Schematic representation of a relationship diagram associated with rating smileys (AccePT method)*

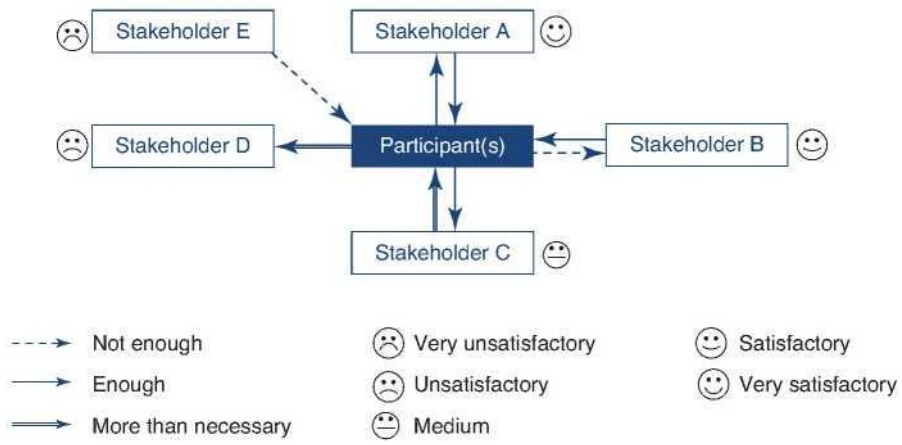

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***Fig. 8.2*** *Schematic representation of a flow diagram associated with proportional stacking (AccePT method) (arrows = relation between actors; dots = level of trust; the increase in dots represent increase in trust level)*

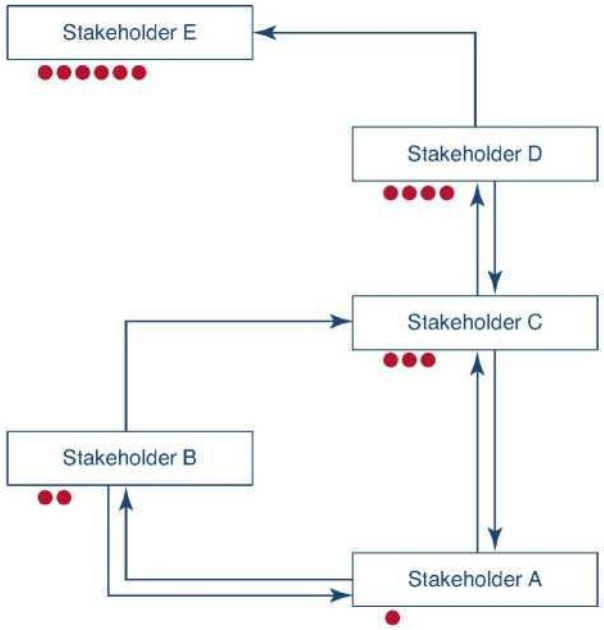
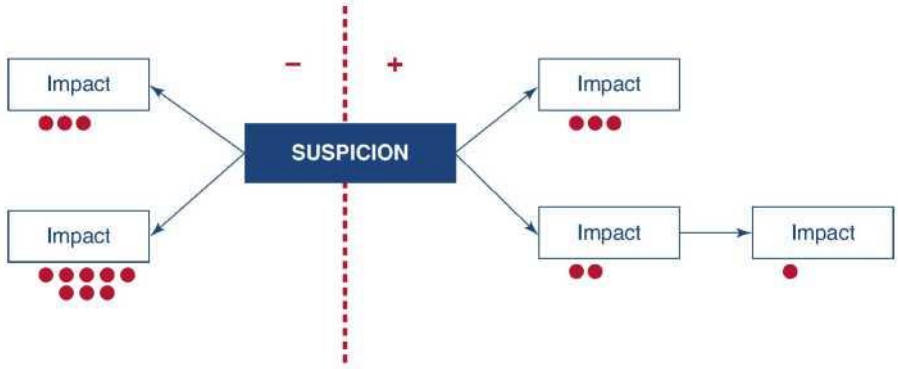



***Fig. 8.3*** *Schematic representation of an impact diagram associated with proportional piling (dots; the highest number = the highest value)*




Once the diagram has been constructed, the participants will again use proportional piling in two stages: first, they are asked to divided 100 game tokens between positive and negative impact to weight them, then in a second step to distribute each pile of token between the different impacts that have been identified by the participants (Fig. 8.3).

***Fig. 8.4*** *Example of representation of the results of the estimation of the acceptability by the use of the AccePT method (case of the surveillance of bovine tuberculosis in Belgium)*

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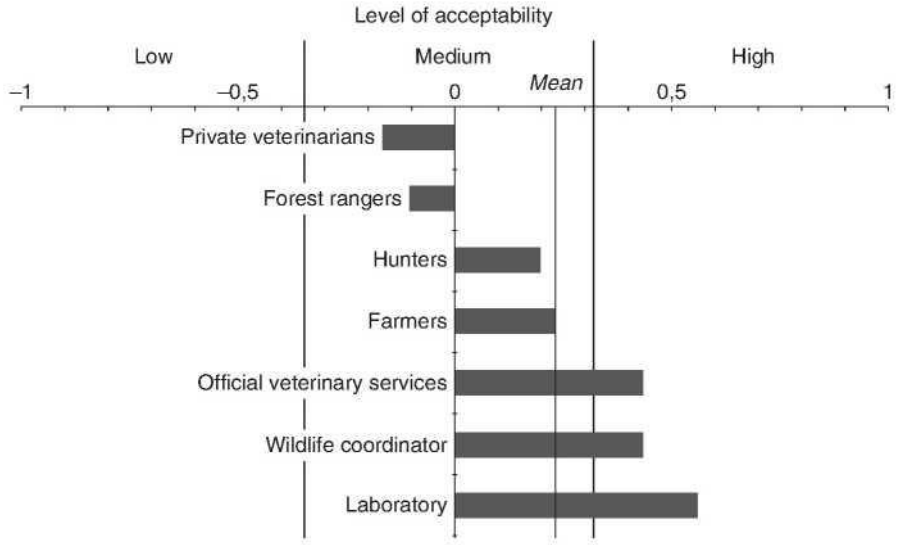


**Analysis and Presentation of Results**

The results of the Acceptability Estimate are based on the analysis of all the discussions that took place between the participants during the interviews, the diagrams, and the semiquantitative data obtained from smiley scoring and proportional piling.

The analysis is carried out initially for each individual interview and each group discussion. An evaluation grid has been developed presenting scoring criteria based on a semiquantitative scale with the following score according to the different element of acceptability index: "unsatisfied = -1, medium = 0, satisfied = 1" for their satisfaction level in the objective, the operation and the information within the system; "weak = -1, medium = 0, good = 1" for their level of trust. Proportional piling analysis was based on the way that participants divided 100 counters between negative and positive impacts. Based on the scoring guidelines, the scores were then categorized into three levels such as weak [0; 33], which is equal to score -1, medium [33; 66], which is equal to score 0, and good [66; 100], which is equal to score 1. The results can be presented in different formats: by type of actor, by level of surveillance (local, regional, national) or by element of acceptability, or even by the combination of these different elements (Fig. 8.4).

The qualitative data collected during the interviews also includes valuable infor-mation for improving the surveillance system. In fact, interviews allow participants to discuss their points of view, expectations, and experiences, which are essential for improving surveillance. Follow-up events to discuss the outcome of the performance evaluation may be very valuable to further discuss the findings and involve additional actors who have not taken part in the process but who may be impacted by the results and the recommendations.

### 8.4.1.4 BENEFITS, LIMITS, AND OUTLOOK

The AccePT method is a standardized method for estimating the acceptability of epi-demiological surveillance systems in animal health taking via participation of the diversity of actors involved in the network. By using different participatory tools and analyzing the results in the form of a scoring grid, it is possible to determine a general level of acceptability of the system, as well as a level of acceptability by type of actors.

The use of this method makes it possible to formulate recommendations that are context-specific, and most of which can be directly formulated by the participants. It also leads to a better acceptability of the evaluation thanks to the direct involvement of the actors in the process. It offers the opportunity to clearly

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document the general context of the surveillance and the structure of the surveillance system. It contributes to strengthening the ownership of the stakeholders in the system and provides capacity-building opportunities regarding specific diseases or epidemiological surveillance generally.

Implementing the AccePT method, however, requires specific training in the use of participatory approaches. In addition, there are substantial time requirements related to the organization of interview sessions, participant recruitment, interviews facilitation, and analysis of the results. Biases related to semistructured interview approaches can also influence the outcomes and further justify the need for appropriate training in participatory approaches. The organization of the different focus group should be organized very early in the process of evaluation in order to target homogenous group to avoid power relationships within interview groups and ensure participants freedom of expression during sessions. Cultural factors, such as the tendency to avoid conflict at all cost and also not wanting others to lose face, may significantly influence the dynamic during interview sessions. Some participants may not want to be seen as being too negative toward other partners and may bias their scoring toward the least conflictual options. Particular care should be used to mitigate the influence this may have on the scoring process.

There is a potential for participatory epidemiology to be valuable in the evaluation of other attributes, such as communication, stability, representativeness, or training provision. These methods could also be used for different issues, such as impact studies of research projects or "One Health" projects (see Chaps. 9 and 16).

The three cases studies presented below confirmed the interest of using these approaches to better identify the actors involved in the operation of surveillance beyond the official system and to specify their roles:

- Take into account stakeholders' perceptions/expectations and thereby improve understanding of the system; issue context-dependent recommendations; better understand the organizational and functional attributes.
- Involve stakeholders directly in the evaluation process, thus identifying potential bottlenecks, ensuring greater acceptability of the evaluation process itself, and fostering the sense of ownership of the system.
- Indirectly generate key information related to the general context and external factors.

## 8.5 Case Study 1: Application of Participatory Approaches to Evaluate Avian Influenza Surveillance in Vietnam

Participatory approaches were applied in a pilot study to evaluate avian influenza surveillance system in Vietnam [30]. The objective of the study was to estimate the performance of the passive reporting system of avian influenza in Luong Dien Commune (located in Cam Giang District, Hai Duong Province) in Vietnam. The specific objective was to assess the occurrence and reporting of sudden death in poultry. The underlying hypothesis was that sudden death is occurring in the com-munity, but is not always reported. The study was conducted in 2012, in three villages of the commune of Luong Dien, Province of Hai Duong, in the Red River Delta of North Vietnam (about 50 km West of Ha Noi). Individual and focus group interviews of local authorities, veterinarians, and farmers were conducted (n = 160 participants) to understand how health information was shared in case of high poultry mortality. Participatory tools such as proportional piling, matrix scoring, mapping, transect walks, Venn diagrams, flow diagrams, seasonal calendar, and disease impact matrix scoring were also used to help in characterizing the system.

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The flow of information sharing varied according to the mortality levels observed and those thresholds were defined locally (Fig. 8.5). If poultry mortality was higher than what was considered as the "normal" situation (>10-15% mortality in the village overnight), farmers would directly ask advice from private drug and/or veterinarian drug sellers. In case of higher mortality (>30% in the village overnight), the event was considered as "epidemic" by the farmer who would inform the village and/or the commune veterinarian for advice (do they need to slaughter the poultry?) and investigation. If the village or commune veterinarian considers that the mortality rate is too important to be manage locally (>50% in the village overnight), he will inform the official district veterinarians by sending an official letter when (considering that there is a risk of H5N1). In this case only, the official surveillance network is activated and the control measures are deployed. This pilot work highlighted two important aspects: (i) the definition of an HPAI suspicion case will vary according to the local situation and is far less sensitive than the official system case (>5% of sudden mortality); and (ii) the reporting system at local level does not follow the "vertical" path of the official passive surveillance system but rather a "horizontal" one for reasons of efficiency, speed, and simplicity; the farmers are looking for quick and nonbinding solutions to the health problems facing him and preferentially turn to local providers of veterinary services (pharmacies, suppliers of inputs). According to the same logic, the official veterinary services can be contacted, but personally, as private service providers.

Compared with traditional surveys based on the use of directed questionnaires and a priori sampling of actors, the use of participatory approaches allowed

- To identify some key actors in the surveillance system that were not mentioned in traditional surveys (e.g., drug vendors and veterinary food wholesalers).
- To clarify the role of the actors in the official system, which is certainly predominant in the exchange of health information but essentially in a private capacity (public veterinarians all have a liberal activity) and this type of information does not therefore follow the official path of notification of sanitary incidents.

This pilot work was subsequently validated and extended as part of Delabouglise et al. work (cf. Chaps. 6 and 11; Delabouglise reference papers).

***Fig. 8.5*** *Health information flow of avian diseases at local and intermediate scales in North Vietnam*

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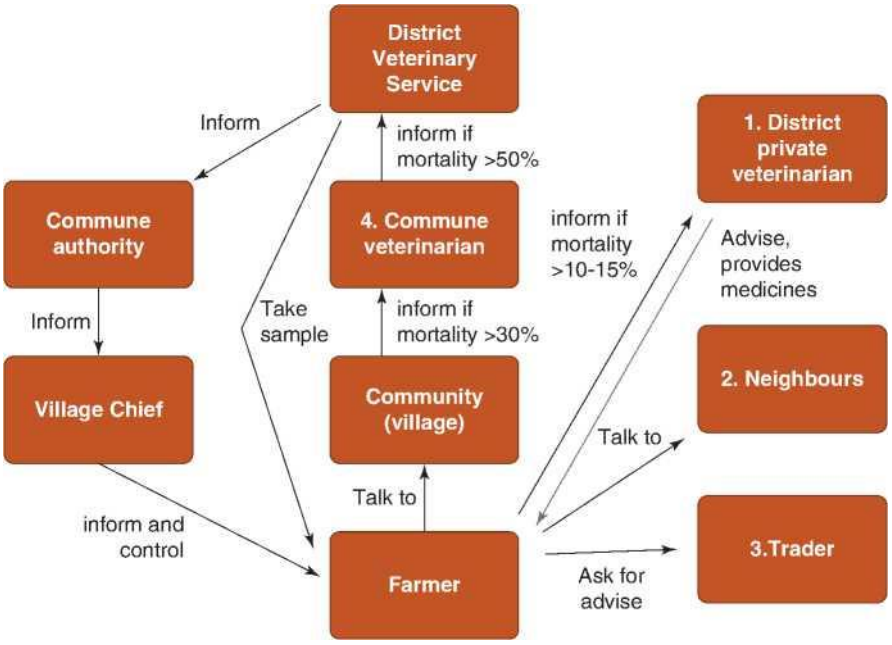


## 8.6 Case Study 2: Evaluation of the Acceptability of Classical Swine Fever Surveillance System in Germany

The AccEPT method was used for the evaluation of the classical swine fever (CSF) surveillance system in Germany, where analysis of the monitoring process by the OASISTrop tool had revealed significant limitations in acceptability of the system by its actors [22]. In an attempt to enhance the system's sensitivity and representativeness, four new monitoring components were designed and compared to the current surveillance strategy. Only the passive component in place and one alternative component (selection of samples based on the age of the animals) have proved to be acceptable to the hunters, actors at the source of the data of the system (Fig. 8.6). This study highlighted the importance of considering this attribute in the selection of surveillance strategies adapted to the actors to ensure its implementation in the field and improvement of the system.

***Fig. 8.6*** *Level of acceptability of different PPPC surveillance strategies in Germany. (From 22)*

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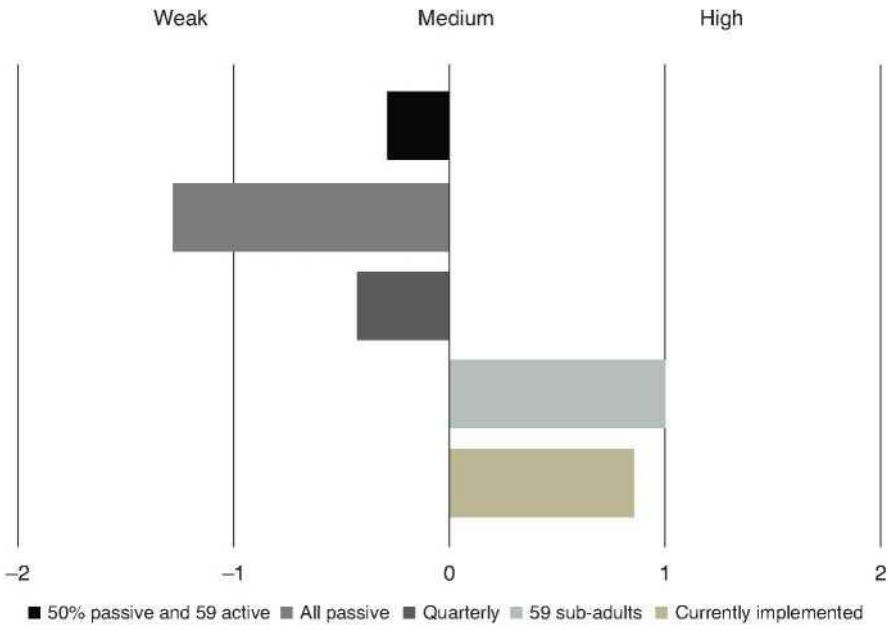


## 8.7 Case Study 3: Evaluation of the Acceptability of a Pilot Multistakeholder Wildlife Health Surveillance Network in Cambodia

The AccEPT method was used for the evaluation of the pilot wildlife health surveillance network in Cambodia, established by WCS under the EU-funded LACANET project. The general objective was to understand the level of stakeholders' willingness to cooperate and to keep their support to the surveillance system. For the total scoring, it can be seen that the participants were satisfied with the system objective, system operation, their own role with the system, relations between stakeholders, and had trust with the system (Table 8.2).

However, if we look in detail at the scores between the different stakeholders we can identify some different levels of satisfaction among them:

- Collaboration between the two wildlife rescue centers was highlighted as important and needed, but mechanisms of efficient dialogue between them still need to be established.
- Provincial animal health agents do not know much about the pilot WHSS and are still reluctant to engage with wildlife health problems in some sites.
- Local authorities are recognized as key partners for wildlife health surveillance. However, field agents in most sites have issue to establish sustainable and efficient collaboration with local authorities because of the lack of direct benefit for them (no clear reward or compensations identified).

***Table 8.2*** *Scoring level of every components measured within the AccEPT method for the pilot wildlife surveillance network in Cambodia, evaluation conducted between mid-April to mid-May 2019 [23]*

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| Row labels | Average of acceptability of the objective | Average of acceptability of the operation | Average of satisfaction of own role | Average of consequence of the information flow/Impact | Average of satisfaction of the relations | Averaged trust devoted in the system |
|---|---|---|---|---|---|---|
| Field Actor | 0.91 | 1 | 1 | 0.09 | 1 | 1 |
| Field Management | 1.00 | 1 | 1 | 1.00 | 1 | 1 |
| Laboratory | 0.50 | 1 | 1 | 1.00 | 1 | 1 |
| Grand Total | 0.86 | 1 | 1 | 0.14 | 1 | 1 |

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