



A review on application of participatory epidemiology in disease surveillance and data collection

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Abstract

Participatory epidemiology is the application of participatory methods to epidemiological research and disease surveillance. It is a proven technique which overcomes many of the limitations of conventional epidemiological methods, and has been used to solve a number of animal health surveillance and research problems. The techniques of participatory rural appraisal (PRA) are used to formulate the programme objectives, gather epidemiological data and intelligence, and analyze information. Participatory epidemiology recognizes that local people have very rich and detailed knowledge about the animals they keep and the infectious and zoonotic diseases that can gravely affect their livelihoods and endanger human health. The basic importance of participation in participatory epidemiology are to avoid failure of projects and activities, to insure local commitment, to enhance local ownership, to recognize cultural sensitivity, to improve sustainability, to ensure the outsiders do not misunderstand needs, to avoid duplication of activity, and to avoid wastage of resources. Participatory epidemiology assumes that surveillance is a set of integrated activities and veterinarians (not community animal health workers) who have been trained in the approach conduct PE investigations.

Keywords: *participatory epidemiology, disease surveillance, data collection*

Introduction

Participatory epidemiology is the application of participatory methods to epidemiological research and disease surveillance. It is a proven technique which overcomes many of the limitations of conventional epidemiological methods, and has been used to solve a number of animal health surveillance and research problems. The approach was developed in small-scale, community animal health programmes, and then applied to major

international disease control efforts. The Global Rinderpest Eradication Program adopted participatory epidemiology as a surveillance tool for controlling rinderpest. This approach was subsequently used in both rural and urban settings in Africa and Asia, for foot and mouth disease, peste des petits ruminants and highly pathogenic avian influenza. Participatory disease surveillance has made an important contribution towards controlling both rare and common diseases (Catley *et al.*, 2004).

Participatory epidemiology is an emerging field that is based on the use of participatory techniques for the harvesting of qualitative epidemiological intelligence contained within community observations, existing veterinary knowledge and traditional oral history (Jost, 2007). Existing veterinary knowledge is specific to each community and utilizes local language terms, but recognizes common clinical presentations, epidemiological patterns of disease, vectors and reservoirs. In the developing world where laboratory data is limited, intelligence derived from participatory studies often provides a more accurate description of disease status. When integrated with targeted laboratory studies, participatory data provides the context for realistic interpretation of laboratory results (Narayanasamy, 2009).

The techniques of participatory rural appraisal (PRA) are used to formulate the programme objectives, gather epidemiological data and intelligence, and analyze information. Participatory epidemiology recognizes that local people have very rich and detailed knowledge about the animals they keep and the infectious and zoonotic diseases that can gravely affect their livelihoods and endanger human health. Local farmers and livestock owners are often able to describe clinical presentations, epidemiological patterns and principal pathological lesions using a vocabulary of specific disease terms in local languages that correspond to Western clinical case definitions. This body of knowledge has been termed existing veterinary knowledge (EVK) (Admassuet *al.*, 2005).

Participatory epidemiology (PE) is the use of participatory approaches and methods to improve our understanding of the patterns of diseases in a population. These approaches and methods are derived from participatory appraisal. Participatory appraisal (PA) is a family of approaches and methods that enable people to present share and analyze their knowledge of life and conditions to plan and to act. It is participatory, flexible, lightly structured, adaptable, exploratory, empowering and inventive. It is also an approach for shared learning between local people and outsiders; and

is one of the best Participatory approaches for disease surveillance and data collection (Catley, 2000). Early applications of participatory epidemiology focused on pastoral communities, whose livelihoods were heavily dependent on livestock and who had limited exposure to Western veterinary medicine. Since then, the approach has been extended to a diverse range of communities that includes mixed livestock agriculture systems and even peri-urban and intra-urban livestock production systems (Chibeu, 2004).

The basic importance of participation in participatory epidemiology are to avoid failure of projects and activities, to insure local commitment, to enhance local ownership, to recognize cultural sensitivity, to improve sustainability, to ensure the outsiders do not misunderstand needs, to avoid duplication of activity, and to avoid wastage of resources. Various methods have been used to assess the impact of veterinary projects. One approach to impact assessment involves an initial comprehensive epidemiological survey of livestock diseases followed by comparison of the disease situation before and after an intervention. While this approach may be recommended from a purely technical perspective, the cost and time inputs required are outside the scope of most community based animal health workers projects in pastoral areas of Africa (Catley and Mariner, 2001).

Pre-requisites for Participatory Appraisal

Participatory appraisal (PA) is used when investigators are willing to let the community take control, when they want to base their actions on local knowledge and when they want to reach out to very diverse members of a community. PA can deliver empowered participants, better relationships between participant groups, reliable and valid mapping of local knowledge and priorities, action and energy, as well as being a good tool to make decisions with. In the short term PA can be used to map local priorities and understandings of issues. In the mid-term, PA should be an ongoing cycle of research, learning

and collective action. The long-term goal of this approach is to empower and enable people to analyze and tackle their problems themselves. A commonly encountered problem is that as PA uses very accessible tools, it is often used as an information providing exercise that does not follow through to facilitate decision-making within the community (Jostet *et al.*, 2007).

Attitudes and Behaviour in Participatory Epidemiology

If informants are concerned that researchers have a 'hidden agenda', they will use the information solely for selfish purposes or if informants consider outsiders to be rude or arrogant, or only interested in their own opinions, the discussion will not be very constructive. Therefore, a crucial feature of participatory epidemiology is that researchers must be constantly aware of their own attitudes and behaviour. Similarly, farmers were experimenters in their own right. They recognised problems and tested different ways to solve these problems. By understanding what farmers already knew and involving them in problem-solving, projects were better tailored towards local perceptions and capacities (Catley *et al.*, 2004).

Informal Interviewing Methods

Informal interviewing is the most important group of participatory epidemiological methods which focuses on groups selected based on type of information required for the investigation. It may be used alone in epidemiological investigations but it is frequently complement and can be the form of the basis for other methods (WOAH, 2014).

Simple Ranking

Simple ranking is arranging items in order based on defined criteria. It is a fast, and easy tool that allows many people to participate. It ensures that consensus is built among the group being interviewed and gives opportunity to probe more deeply into the meaning behind the ranking (Mariner, 2000).

Pair-wise Ranking

Pair wise ranking /comparison is a slightly more complex method of ranking where each item is compared individually with all the other items one-by-one to generate an overall ranking. It helps to understand the benefits of different species or the impact of different diseases, and used when the results from the simple ranking and proportional piling are not conclusive (Catley, 2002).

Proportional Piling

Proportional piling is a technique that allows farmers to give relative scores to a number of different items or categories according to one criterion. The scoring is done by asking the farmers to divide 100 counters into different piles that represent the categories according to their importance using differ parameters. In this technique, the participants are given a number of counters (for example, 100 beans) and asked to divide them into piles, representing a number of categories, by agreed criteria. For example, the community may have identified five principal poultry diseases. Respondents could then be asked to divide the pile into five smaller piles, to represent the relative impact of each disease on their livelihood. Proportional piling techniques can be adapted to study issues such as: disease prevalence and incidence, mortality rates, clinical presentation, epidemiological risk factors, disease impact, and the efficacy of disease interventions (Loewenson, 2004).

Matrix Scoring

Another visual scoring method which compares at least two indicators is matrix scoring, where a two-dimensional grid is used to score items by at least two sets of categories. The researcher can use the completed matrix in short, semi-structured interviews to follow up interesting results and cross-check information (Mariner 2001).

Participatory Mapping

Participatory mapping is used to define the population and system under investigation. It provides spatial information about the investigation area; its key features, natural resources, agriculture, markets, etc. Participatory mapping can show the location of disease outbreaks, how disease spreads through an area, disease risk areas, and livestock movement and contact with other groups. It can use different scales depending on the study objective e.g. farm, village, kebele, district, region (Admassuet *al.*, 2005).

Participatory Evaluation

Participatory evaluation involvement can occur at any stage of the evaluation process, from the evaluation design to the data collection and analysis and the reporting of the study. A participatory approach can be taken with any impact evaluation design, and with quantitative and qualitative data. However, the type and level of stakeholder involvement will necessarily vary between different types, for example between a local level impact evaluation and an evaluation of policy changes. It is important to consider the purpose of involving stakeholders and which stakeholders should be involved how in order to maximize the effectiveness of the approach (Gujit 2014; Campilan, 2000).

Conclusion

Participatory epidemiology is the application of participatory approaches to improve the understanding of the animal disease situation. A key feature of PE is triangulation or crosschecking information derived from multiple sources and methods. This includes conventional approaches such as clinical and pathological examination, and laboratory diagnosis. Participatory epidemiology assumes that surveillance is a set of integrated activities and veterinarians (not CAHWs) who have been trained in the approach conduct PE investigations. It is important to consider the purpose of involving stakeholders and which stakeholders should be involved how in order to maximize the effectiveness of the approach.

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