From Marginal to Normative: Institutionalizing Participatory Epidemiology

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Abstract

Participatory epidemiology (PE) is now widely used by veterinary researchers, epidemiologists and other workers in east Africa, and is taught in veterinary schools in the region. This paper describes how the use of participatory approaches by veterinarians has grown during the last ten years or so, and how specific strategies and processes were used to raise understanding of PE, and promote field testing and assessment within different organizations. The value of PE in terms of delivering benefits to livestock keepers partly depends on how veterinarians and epidemiologists work with communities to identify research topics and prioritize diseases, and the action which follows PE research or assessments.

Introduction

By the mid 1990s participatory approaches and methods were being used by many small-scale community-based livestock projects. Experiences were documented in a special livestock edition of *RRA Notes* in 1994 and included the use of RRA and PRA methods to prioritize and map livestock diseases. Although community-based and participatory approaches to veterinary care became increasingly popular at this time, veterinary uses of participatory approaches and methods remained localized in the NGO community, and were not widely adopted by research centers, veterinary schools or government veterinary services.

Just over ten years later a new edition of the well-known veterinary textbook *Veterinary Epidemiology* included a section on 'participatory epidemiology' (PE) based on the use of adapted RRA/PRA methods (Thrusfield, 2005). By mid-2007 at least four African veterinary schools were teaching PE at either undergraduate or postgraduate level, and capacity-building in PE was a common feature of programs intended to strengthen government disease surveillance systems in Africa and beyond, including Europe. Participatory epidemiology was being used in impact assessment of veterinary interventions, disease investigation, and epidemiological and economic studies. For some issues, information derived from PE was pivotal for informing policy dialogue and reform. But how did this transformation come about? This paper describes some of the strategies and processes which were used to test and promote the use of PE in veterinary institutions in east Africa. The paper also presents some current challenges facing the application of PE and ensuring benefits to communities.

Strategies for institutionalizing participatory epidemiology

1. Understand the concerns of the 'veterinary establishment'

In the mid 1990s participatory approaches and methods were normal practice in many disciplines and sectors but were yet not widely used by veterinarians. For example, in 1995 the World Health Organization published guidelines for rapid participatory appraisal to assess human health needs (Annett and Rifkin, 1995) but a year later the equivalent UN livestock institution – the Food and Agriculture Organization – was only just becoming aware of the value of community participation in veterinary services (Leyland, 1996). In most government veterinary services and veterinary schools in Africa, awareness of community participation or approaches such as PRA was very limited.

Due to the apparent delays in support to approaches such as PRA by the veterinary establishment, in the late 1990s the International Institute for Environment and Development began a project with the Organization of African Unity[ii]/Interafrican Bureau for Animal Resources to examine options for the wider use of PRA-type approaches in veterinary institutions in Africa. Called the 'Participatory Approaches to Veterinary Epidemiology' (PAVE) Project, the first stage of the project was a survey of

attitudes and understanding of participatory appraisal among veterinarians working throughout Africa, in various organisations (Catley, 2000). The survey showed that although veterinarians acknowledged that participatory approaches could improve links between professionals and communities, among the main concerns and constraints were the qualitative nature of the data derived from participatory methods, the limited availability of training courses and literature, and negative attitudes towards PRA among colleagues and managers.

To some extent, the concerns of veterinary researchers and epidemiologists about RRA/PRA were justified. For example, in the growing informal literature on veterinary uses of RRA/PRA there was often no mention of triangulation or cross-checking of results. So although veterinarians were using RRA/PRA, rarely did they report clinical examinations of livestock or use basic disease investigation techniques to support their reports. This is not say that conventional and time-consuming disease surveys were needed alongside RRA/PRA work, but that occasionally, some basic veterinary professional diagnosis would have added greatly to the validity of the findings. When RRA/PRA was used by non-veterinarians to understand livestock diseases, in some cases the interpretation of information provided by informants was simply wrong.

Discussion with veterinary researchers and epidemiologists soon after the publication of the initial PAVE survey also indicated that these workers felt that the qualitative nature of RRA/PRA hindered publication in scientific journals. Within their various organisations, career development was partly dependent on research publications in peer-reviewed journals. Organizational incentives focussed on the number of publications and the journals used, rather than the impact of the research on communities. These experiences indicated that strategies for introducing RRA/PRA approaches in veterinary institutions needed to include options for adapting some participatory methods into more quantitative tools, and showing how research using RRA/PRA could be published. It was also evident that more profound institutional change was required to change the incentives which governed the ways in which research topics were identified, and the research approaches and methods which were used.

The next stage of the PAVE Project made a deliberate attempt to create a branch of RRA/PRA that veterinarians might call their own. The term ‘participatory epidemiology’ (PE) was used by PAVE in an attempt to combine the language of participation with a scientifically-recognized discipline. In the late 1990s veterinary epidemiology was largely perceived as a quantitative subject, although it had a history of borrowing methods from the social sciences (Schwabe, 1982).

2. Playing the numbers game: studies on the validity and reliability of participatory epidemiology

In response to some of the concerns outlined above, in 2000 and 2001 the PAVE Project conducted field research in Africa to assess the reliability and validity of PE methods. The general approach was to compare data derived from PE with data produced by conventional livestock disease investigation and epidemiological methods (Table 1).

<insert Table 1>

An important aspect of the PAVE studies was to examine when and how to standardize PE methods, to explore the pros and cons of standardization, and to analyze and present the results in different ways for different users. For methods which produced numerical data (e.g. matrix scoring, proportional piling) the approach was to identify the minimum number of repetitions which would allow the analysis and presentation of results using conventional statistics. For these methods, it was also possible to standardize while at the same time, allow flexibility. A matrix scoring method might use some items and indicators which were fixed (standardized) by the researchers, while also allowing informants to add their own items or indicators. The use of informal interviewing as part of a method such as matrix scoring allowed flexible follow-up of interesting results. Some matrix scoring results from PAVE are shown in Figure 1.

<insert Figure 1>

Another key finding from the PAVE studies was that some PE methods were more valid than conventional methods such as questionnaires. A good example was the use of proportional piling to

assess livestock disease incidence and mortality with pastoralist communities. The proportional piling methods tested by PAVE used local disease terminology, local livestock age categories, and as a proportional method, avoided sensitive questions on the absolute number of livestock owned by an informant. An example of results derived from proportional piling is shown in Figure 2. Over time, matrix scoring and proportional piling were used not only to measure important epidemiological variables, but also, to explore association between disease and possible causal factors.

<insert Figure 2>

In terms of assessing the validity of PE, the PAVE Project used a variety of conventional veterinary diagnostic methods, from clinical examination of livestock by a veterinarian to the use of laboratory tests. The project also used matrix scoring to compare the characterisation and clinical diagnosis of diseases by pastoralists and veterinarians, and used quantitative analytical methods to show the similarity in clinical diagnostic ability between these two groups (Catley, 2006).

3. Targeted publications and peer-review

A specific strategy of the PAVE project was to publish the results of field studies in respected peer-reviewed journals. All three of the field studies in PAVE were published in peer-reviewed journals (Table 1) to ensure that PAVE studies were subject to expert assessment and to raise awareness and acceptance of PE among academics and researchers.

4. Strategic training and experiential learning

From 2002 to 2004 the Pan African Programme for the Control of Epizootics[iii] supported a series of PE training and mentoring activities in east Africa. Drawing on experiences of institutionalizing participation in government bureaucracies (Thompson, 1995), CAPE aimed high. It assumed that within government veterinary services or veterinary schools, space for testing and discussing PE would not emerge unless senior managers had some understanding of PE approaches and methods. Therefore the first PE training course targeted national government epidemiologists and senior academic staff from veterinary schools from Eritrea, Ethiopia, Kenya, Sudan, Tanzania, Uganda and Somalia. Some specific elements of the training were:

- An initial focus on attitudes and behaviour, and the value of indigenous knowledge on livestock diseases.
- A comparison of the process of triangulation in PE and conventional veterinary diagnosis. The latter combines different methods and types of information to reach a diagnosis, and is a qualitative process used by practising veterinarians almost daily.
- A comparison of optimal ignorance in PE with modern medical or veterinary practise. In the management of many medical or veterinary cases, clinicians rarely identify a specific disease agent – they simply treat the main symptoms.
- Analysis of peer-reviewed PAVE studies (as listed in Table 1) leading to a realisation that it was possible to combine qualitative and quantitative data derived from PE, and also to publish in scientific journals.
- The role of conventional veterinary diagnostic or epidemiological methods to complement PE, often as one type of triangulation. This attention to the complementary nature of PE helped to remove fears that PE should replace conventional approaches.
- Field testing of PE methods during the training, and placing trainees face-to-face with livestock keepers.
- Attention to forms of PE that were purely qualitative but still very useful. In particular, the use of participatory disease searching during rinderpest eradication programmes was presented and discussed as an inductive, investigative approach.
- Discussion on how PE could be used to add value to the work of the trainees when they returned home.

Follow-up activities after the training included support to postgraduate programmes in veterinary schools in Addis Ababa and Nairobi. Masters students conducted research in pastoralist areas and results were presented in dissertations (Eregae, 2003; Lotira, 2003; Mochabe, 2003; Titus, 2003; Dejenu, 2004; Gizaw, 2004; Rufael, 2006), and in some cases, peer-reviewed journals (Mochabo et al. 2004, 2006; Rufael et al., 2008). The process of supporting postgraduate students was useful not only due to the experiential learning for the students themselves, but also because their academic

supervisors were required to assess PE as an epidemiological approach. Other postgraduate research was later conducted in Kenya (Bedelian, 2004), Nigeria (Idowa, 2005) and Sudan (Elnarsi, 2006), supported by universities in Edinburgh, Ibadan and Khartoum respectively.

5. Continuous adaptation, wider application and policy influence

Over time, uses of PE have become more diverse. By 2007 PE methods had been adapted for use in the impact assessment of community-based animal health projects (Admassu et al., 2004; Dejenu, 2004), disease modelling studies (Mariner et al., 2005), cost-benefit analysis of vaccination programmes (Barasa et al., 2005), and the impact assessment of livestock vaccination during drought in pastoralist areas (Catley et al., 2008).

These studies are cited not only because they show adaptation of PE, but also because they influenced policy. In Ethiopia, the assessment of community-based animal health workers (Admassu et al., 2004) was one piece of evidence which led to their legal recognition. Also in Ethiopia, retrospective cohort studies using PE methods showed the limited impact of vaccination on livestock mortality during drought (Catley et al., 2008) and prompted various international and national actors to revise vaccination strategies and best practice. In east Africa, modelling studies on rinderpest (Mariner et al., 2005) helped to raise awareness of issues such as the role of low vaccination coverage in maintaining the disease in pastoralist areas. The cost-benefit analysis of foot and mouth disease in South Sudan (Barasa et al, 2005) produced results which showed that contrary to much professional veterinary opinion, the disease had an important impact on livelihoods and that vaccination made economic sense. Therefore, in areas where it was very difficult to use conventional research methods PE was beginning to fill important information gaps.

The value of PE has also been shown by its use beyond Africa and its promotion by international actors such as the Food and Agriculture Organization and the International Livestock Research Institute (Grace 2003a, 2003b). The approach has been used in the rinderpest eradication programme in Pakistan, for avian influenza surveillance in south-east Asia, and for foot-and-mouth disease surveillance in eastern Turkey.

Challenges and future directions

The emergence of RRA, PRA and the wider group of participatory learning approaches was intended to improve the relevance and impact of development on poor people. In the area of veterinary medicine, has PE achieved this and if so, how? At one level veterinarians continue to use RRA/PRA methods for the design and evaluation of community-based animal health systems, and in terms of impact this is perhaps the application of PE in its simplest and most useful form. In the last few years, community-based approaches have become much more accepted by the veterinary establishment, and community-based animal health workers are now recognised as one type of veterinary paraprofessional by the World Organisation for Animal Health. If these approaches can be further scaled-up, basic PE has a role to play in designing and assessing community-based delivery systems.

At the level of disease control policies and strategies, PE studies have helped to fills gaps in knowledge on the epidemiology and economics of important livestock diseases in marginalized areas, as prioritised by both livestock keepers and veterinarians. Well-designed and focused studies have contributed to policy debate and often provided evidence and insights from areas where conventional epidemiology was very difficult to use. In many cases, PE methods have proved to be far more useful than questionnaires because many epidemiological questions are well-suited to the visualization and scoring methods of PE, and PE uses local language. Research on disease control options seemed to be most valuable when it responded to local priorities and was directly linked to existing community-based delivery systems, thereby enabling the rapid application of results. Therefore, when used well PE has much in common with participatory research (Conroy, 2004) and can lead to improvements in disease control, with associated benefits to livestock keepers.

As with many other types of participatory learning approaches, PE can be as extractive and data-driven as conventional research and like RRA and PRA, it requires proper training of practitioners and field experience. In common with many other participatory approaches and methods, the issues facing PE are still largely institutional, not methodological. While some research institutions are moving towards incentive arrangements which reward participatory research on animal health (e.g. Okuthe et

al., 2003), much veterinary research is conceived and implemented with very limited understanding of the needs of poor livestock keepers. There is also the challenge of balancing the concerns of the international community, and local priorities. In international efforts such as the Global Rinderpest Eradication Programme, rinderpest was a disease which was prioritized by livestock keepers, government and international agencies. In the Horn of Africa therefore, participatory approaches were used to good effect in rinderpest eradication in very difficult operational environments, and included community-based delivery systems and participatory disease searching. Other diseases may be of far more interest to international and national actors than to livestock keepers. An example is highly pathogenic avian influenza which currently attracts substantial donor investment. Community-level prioritization of this disease is likely to vary considerably between and within countries and therefore, surveillance and control efforts are likely to become more top-down than bottom-up. In these situations, 'participatory' risks becoming a misnomer.

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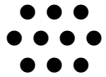
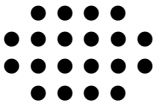
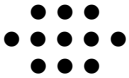
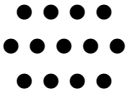
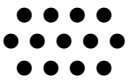
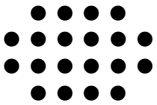
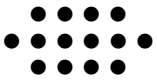
Table 1
Studies on the reliability and validity of participatory epidemiology

Research summary	Research partners
Diagnosis of a chronic wasting disease in cattle, South Sudan (Catley et al. 2001; 2002b).	Operation Lifeline Sudan (Southern Sector) Livestock Programme; Veterinaries sans frontieres-Switzerland; Save the Children UK.
Local characterisation of bovine trypanosomiasis and preferences for disease control, Kenya (Catley et al., 2002a).	Kenya Trypanosomiasis Research Institute; Catholic Relief Services; Diocese of Malindi
Diagnosis of a heat intolerance syndrome in cattle and association with foot-and-mouth disease, Tanzania (Catley et al, 2004).	Faculty of Veterinary Medicine, Sokoine University of Agriculture; Mwanza Veterinary Investigation Centre

Figure 1
Matrix scoring of disease signs for diseases of adult cattle in Nyal (a Nuer area in South Sudan, 1999)

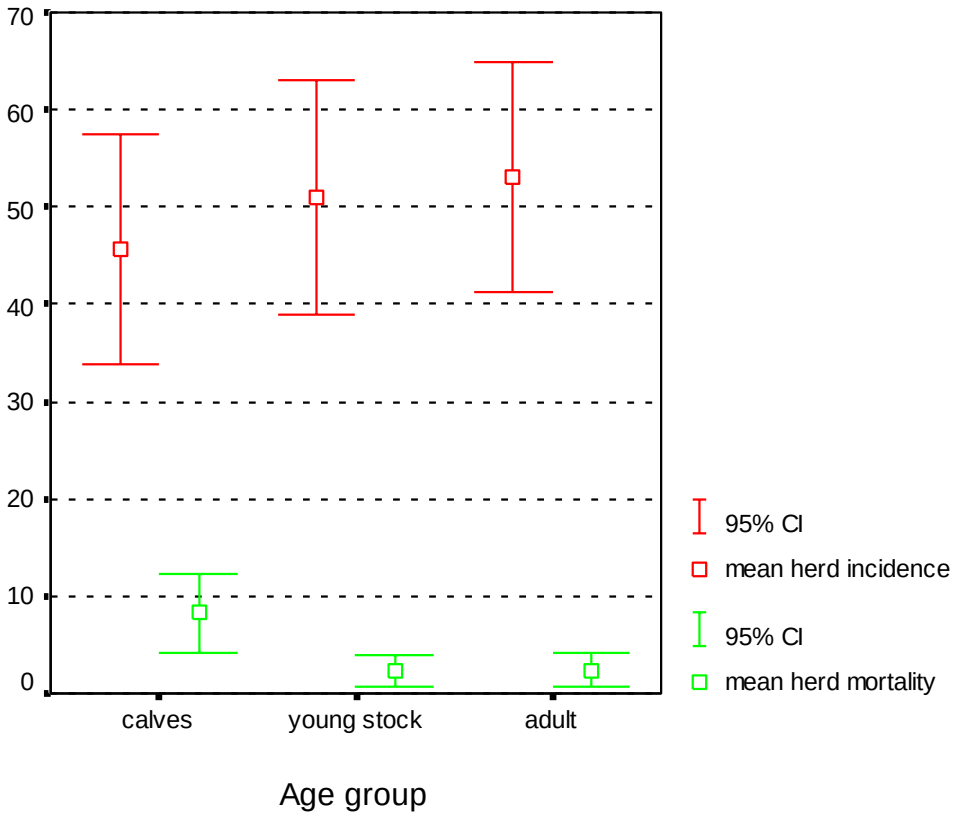
Clinical signs	Nuer cattle disease names				
	Liei	*Dat*	*Maguar*	*Doop*	*Macueny*
Chronic weight loss (W=0.51***)	 10 (6.0-16)	1 (0-2.5)	 3 (0-3.0)	1 (0-2.5)	1 (0-2.0)
Animal seeks shade (W=0.88***)	0 (0)	 20 (17-20)	0 (0)	0 (0-3.0)	0 (0)
Diarrhoea (W=0.52***)	 4 (0-8.5)	0 (0)	 11 (6.0-16)	0(0)	 4 (0-7.5)
Reduced milk yield (W=0.51***)	2 (0-4.0)	 13 (7.0-20)	 3 (0-9.0)	1 (0-2.5)	0 (0-1.0)
Coughing (W=0.76***)	0 (0-0.5)	0 (0-0.5)	0 (0-2.0)	 19 (16.5-20)	0 (0-0.5)
Reduced appetite (W=0.54***)	0 (0)	 13 (7.0-20)	0 (0)	 5 (0-10)	0 (0)
Loss of tail hair (W=0.89***)	 20 (16.5-20)	0 (0)	0 (0-3.5)	0 (0)	0 (0)
Tearing (W=0.28*)	 6 (3.0-13)	2 (0-6.5)	 4 (0-8.5)	0 (0-1.5)	 3 (0-8.0)
Salivation (W=0.50***)	2 (0-3.0)	 14 (7.0-20)	 3 (0-6.5)	1 (0-2.0)	0 (0-0.5)

Notes for Figure 1

Number of informant groups = 12; *W* = Kendall's Coefficient of Concordance (*p<0.05; **p<0.01; ***p<0.001). The black dots represent the scores (number of seeds) that were used during the matrix scoring. In cell of the matrix, median scores are presented with 95% confidence limits in parentheses.

Source: Catley et al. 2001.

Figure 2
Estimates of the incidence and mortality of foot-and-mouth disease in Maasai herds in Tanzania



Notes for Figure 2
Results derived from proportional piling of cattle diseases by age group with 50 individual informants. Local disease names and local definitions of cattle age groups were used.

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[ii] Now the African Union/Interafrican Bureau for Animal Resources
[iii] More specifically, a project called the Community-based Animal Health and Participatory Epidemiology project funded by DFID.