

Review Article



Where is the Participation in Participatory Epidemiology? How Engagement with Social Science could lead to Improved Understanding and Control of *Peste des Petits Ruminants*

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Abstract | *Peste des Petits ruminants* (PPR) is a potentially lethal, highly contagious viral disease of sheep and goats. Domestic sheep and goats are important species for the livelihoods of poor people in many developing countries. Within societies where PPR is now spreading, poverty is widespread and the disease is expected to have significant negative impacts on livelihoods. In resource-constrained marginalised societies, it is often difficult to collect disease data in conventional ways. Participatory epidemiology (PE) has been suggested as a particularly suitable research method to study epidemiology and social impacts of diseases in these contexts. However, for PE to achieve its full potential, stronger efforts to achieve true participation and to incorporate lessons about participation and power from the social sciences may be required. This review shows that social science engagement in PE to date is virtually non-existent, but that increased efforts to draw lessons from the social sciences and to increase the degree of participation in PE could increase its potential as an important tool in disease impact assessment and control. Particular attention is paid here to the potential role of PE in future research on the epidemiology and control of PPR.

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P*este des Petits ruminants* (PPR) is an economically important and highly contagious viral disease of sheep and goats. It is the fourth most important disease of small ruminants world-wide, based on losses of livestock units (World Bank, 2011). Domestic sheep and goats are important species for poor people in many developing countries, where farming and animal husbandry make a critical contribution to the livelihoods of a significant share of households. In particular, the poorest groups in such smallholder farming societies, who have limited possibilities to invest in larger and higher value animals, depend on sheep and goat rearing (Perry et al., 2002). Thus

the spread of PPR could have a particularly negative impact on the poorest and, consequently, controlling PPR can be expected to bring increased livelihood security to many of the rural poor.

In the kinds of societies where PPR is now spreading, it is often difficult both to collect data and to implement disease control strategies in conventional ways, due to lack of infrastructure and lack of established systems for, and local experience of, collecting reliable quantitative data. Participatory epidemiology (PE) has been suggested as a particularly suitable methodology for both implementing disease control practices

and for researching the epidemiology and social impacts of diseases in such contexts (Leach and Scoones, 2013; Catley et al., 2012; Mariner et al., 2012). PE has its roots in participatory rural appraisal (PRA) (Chambers, 1994), an interdisciplinary methodology which in recent years has benefited from significant scrutiny and revision through its engagement with social science (Kapoor, 2002). This paper reviews the social science engagement to date in PE, as a branch of PRA, and examines how increased efforts to draw lessons from the social sciences and truly include local participation in PE could improve its potential as an important tool in disease impact assessment and disease control. To suggest how a social science engaged version of PE might in practice improve research and advisory work in animal disease control and prevention, here we use PPR as an example. PPR is a priority disease in the FAO-OIE Global Framework for the Progressive Control of Transboundary Animal Diseases (FAO and OIE, 2015). It has been suggested that to successfully eradicate PPR, a better understanding is needed of marginalised farmers' practices and perspectives, and how their possibilities to act on disease are affected by local institutions and power relations (Mariner et al., 2012).

Current Global Status of PPR

The PPR virus infects and gives rise to disease in a wide host of even-toed ungulates, *e.g.* sheep, goats, antelopes, deer, wild goats and camels. Large ruminants such as cattle and African buffalo can seroconvert, but do not show clinical signs (Abubakar et al., 2011; Furlley et al., 1987; Kock et al., 2006). The clinical signs of PPR include pyrexia, ocular and nasal discharge, dyspnoea, pneumonia, diarrhoea, severe lethargy and decreased production, with some animals succumbing to the disease and dying within 10–12 days, due mostly to severe dehydration (Munir et al., 2012). Morbidity and case fatality rate can both vary between 10 and 100 % depending on previous immunity, age and species of animals infected (Munir et al., 2013; Roeder and Obi, 1994). The disease is spreading rapidly despite the availability of effective vaccines and diagnostic tools for control.

PPR was first described in West Africa in the 1940s and has since then spread geographically, particularly during the past 15 years. The disease is now reported to be present in about 70 countries world-wide, with more than 60% of the countries currently affected be-

ing in Africa. The disease is present in some countries in North Africa and in all Eastern, Central and West African countries. Although most countries in Southern Africa are currently free from PPR, there is a high risk of it spreading further south. PPR is widespread in the Middle East and South Asia, with South East Asia as the exception. In Central Asia spread is more limited. In Europe there is no circulation of the virus, but with the disease is now present in western Turkey and in North Africa, the possibility of spread into Europe cannot be ignored. In 2007 PPR was reported in China for the first time and by 2013, 22 of the 31 Chinese provinces were infected (FAO and OIE, 2015).

Failure to manage PPR may be linked to cessation of rinderpest vaccination, which was cross-protective and widely applied to domestic sheep and goats, and to general inattention to the small ruminant sector (Perry et al., 2002). Lack of sufficient resources in the veterinary service system in many of the affected countries is most likely also contributing to the current failure to manage PPR (Perry et al., 2013; Perry and Grace, 2009; Forman et al., 2012; de Balogh et al., 2013).

PPR and Poverty

Compared with larger livestock, goats and sheep are commonly affordable even to the poorest, for whom they provide important livelihood security (De Haan et al., 2015; FAO, 2013; Perry et al., 2002; Herrero et al., 2013). The animals owned by poor households often enter the formal economy only to a limited extent and are instead frequently used in bartering, for ceremonial purposes, for paying traditional doctors, for dowry etc. The comparatively low value and fast reproduction cycle of sheep and goats also means that poverty-constrained households rarely choose to spend scarce household resources on services to prevent, diagnose and treat diseases in these animals. Even when owned by less poor households, sheep and goats are given lower priority than larger livestock as regards paying for veterinary services (FAO, 2013). In addition, sheep and goat production is not always prioritised by the relevant authorities and by veterinary and animal health service suppliers (Metha, 2015). As a consequence of the limited interaction between veterinary and animal health service suppliers and goat and sheep owners, death or reduced productivity of these animals due to PPR, and other diseases, can

easily be overlooked. It has been concluded that to gain control and thus minimise the negative impacts of PPR (and other relevant sheep and goat diseases), there is a need for better understanding how poor and marginalised groups act on animal diseases (FAO, 2013; EuFMD/FAO, 2011). Indeed, research on rinderpest eradication has suggested that engagement of poor and marginalised animal owners might be more efficient for disease surveillance and control in these contexts than conventional methods (Mariner et al., 2012). Against this background, participatory research with smallholders may be particularly suitable for impact assessment and control of PPR. In this paper, we examine whether increased engagement within PE with the social science debates on participatory research and research on marginalised groups has the potential to facilitate the development of such research and, by extension, the eradication or control of PPR. More generally, we consider whether engagement in PE research with the social sciences also has the potential to produce results that are increasingly relevant for facilitating the control of animal diseases and improvement of animal health in poor communities.

Development of PE and Social Science Engagement

According to Catley et al. (2012), PE emerged from PRA approaches developed by Chambers and colleagues in the 1980s and 1990s. Participatory methods in that tradition (commonly referred to as PRA and rapid or relaxed rural appraisal, RRA) (Chambers, 1994) became very popular in the 1990s for making policy and research more sensitive to local conditions (Kapoor, 2002). These methods, and the associated perspective that local people possess important knowledge of their own situation and their environment, had a significant impact on making development work and research more attuned to poor people's realities (Pretty, 1995; Chambers et al., 1989). The introduction of these new approaches also helped make agricultural and rural development research better equipped to understand local situations (Chambers et al., 1989). PE branched off from mainstream PRA during the 1990s, at a fairly early stage of its development. Catley et al. (2012) report that since then, PE has developed in tandem with conventional methods in veterinary science. Much attention in the development of PE has been devoted to getting the method accepted by the conventional research community.

This has been addressed by finding robust ways to 'validate' the results from PE, *e.g.* through combining it with conventional scientific methods and through producing quantitative or semi-quantitative results that can be analysed using statistical methods (Catley et al., 2012). Although this is an important part of methodological development, it can be argued that by branching off from its parent methodology so early and by mainly being influenced by natural science perspectives and quantitative methods, in contrast to traditional PRA, PE has missed out on the important academic scrutiny and revision to which participatory research as a field within the social sciences has been subjected (Calderon, 2013; Pain, 2004; Kapoor, 2002; Jacobson, 2013). For example, Catley et al. (2012) point out that many researchers in veterinary medicine claim to engage in PE, but that the participatory component is practically non-existent or only used for extracting local information.

One reason for the widespread use of this form of PE with very limited participation could be that despite its shortcomings as regards involving local people, it has been successful in extracting data in contexts where other forms of data have been difficult to collect (Chenais et al., 2015a). Thus, PE has mainly been applied in studies of (frequently neglected) diseases in areas where conventional data are scarce, which is often the case in poor and marginalised settings (Leach and Scoones, 2013; Catley et al., 2012). As PE emerged, it often became the method of choice for research on infectious diseases in low-income countries, and thus successfully served to increase data collection on emerging diseases (Hussain et al., 2008; Jost et al., 2010) and endemic diseases (Grace et al., 2009; Robyn et al., 2012). It also played a crucial role in the eradication of rinderpest (Mariner et al., 2012; Mariner et al., 2003). These substantial achievements using PE should be rightfully acknowledged, but in order to move forward from using PE for collecting disease data, extracting information and surveillance to using it in impact assessments, disease control and, ultimately, poverty mitigation, true participation is needed. Applying PE with limited participation misses the core point of PRA, which is to empower local communities through engaging them fully in research (Chambers, 1994).

At the core of PRA is the idea that participatory research and development work achieves outcomes that are locally relevant and often produces more accurate

findings by fully including local people's perspectives and knowledge (Chambers et al., 1989; Scoones and Thompson, 2009). The importance of community involvement and true participation and the need for profound involvement of social science approaches in disease control became painfully evident during the recent Ebola outbreak in West Africa (Richardson et al., 2015). A number of studies describe how human behaviour drove transmission of Ebola virus and show how a multi-disciplinary, or biosocial, bottom-up, community-centred approach drawing on social science competence was fundamental in achieving control of the disease (Ravi and Gauldin, 2014; Roca et al., 2015; Abramowitz et al., 2015a; Abramowitz et al., 2015b).

Furthermore, scrutiny and revision of participatory methodology within the social sciences have had an important influence in making PRA more sensitive to local dynamics and power relations within rural smallholder communities (Jacobson, 2013), which has significantly improved the relevance of the methodology to a wider array of smallholders. Criticism of early PRA work (and of contemporary work which did not take this criticism seriously) stemmed from various PRA tools often being applied without researchers and development practitioners reflecting directly about the process or the methodology as such. As a result, much of the work failed to acknowledge the effect of local power relations, or the effects of the researcher on the outcomes (Pain, 2004; Kapoor, 2002). In essence, the uncritical use of participatory tools has been accused of reinforcing existing power relations, failing to lead to the intended bottom-up change and failing to produce reliable and valid data for research (Kapoor, 2002; Pain, 2004). All societies contain a range of people with different interests, possibilities and perspectives, and no society is exempt from inequality and power relations. Indeed, inequality is often more pronounced in poverty-stricken societies. This means that it is not sufficient to simply engage with 'local communities'. Instead, researchers must seriously take into consideration the fact that different groups of people within communities have different knowledge, differing access to information and different possibilities to claim their rights. Perhaps most importantly from a PE perspective, those who are most affected by a particular animal disease might be those least easily accessed. Therefore dedicated engagement is needed from PE researchers to reach relevant groups (this is admittedly acknowl-

edged by Cately et al. (2012), but the issue has not been significantly scrutinised within PE research). This is of particular relevance for diseases such as PPR, as the small ruminants affected are often of significant importance for the livelihoods of the poorest and most marginalised rural households.

Recent Engagement of PE with the Social Sciences

To obtain an indication of the existing social science engagement in PE, we performed an iterative search for social scientific journal publications addressing the topic. First we searched abstracts, titles and key words in the search engine Scopus for the term "participatory epidemiology" in journal publications from 1 January 2005 to 19 January 2016 [2005 was the year when the Participatory Epidemiology website was set up and when very few journal papers were available as yet, according to the website <http://www.participatoryepidemiology.info/Resource/papers.html>]. In order to identify PE publications engaging with social science research and/or including social science scholars, the search was limited to the "social science and humanities" group in Scopus, which includes publications in arts and humanities, business, management and accounting, decision sciences, economics, econometrics, finance, psychology, social sciences and multidisciplinary research [Any one publication can be classed under several disciplines or sub-disciplines, which means that publications in e.g. veterinary or medical sciences which somehow engage with social science can also be found in the "social sciences and humanities" group]. The search produced four hits (Catley et al., 2009; Catley et al., 2014; Coffin et al., 2015; Goraya et al., 2013), from a total of 44 hits when the subject area was not limited. A search for "participatory epidemiology" in Google Scholar on 19 January 2016 and a browse through the author lists and abstracts of the first 50 hits produced no additional hits. Finally, since one of the hits in Scopus (Coffin et al., 2015) was published in a special issue of the journal *Social Science and Medicine*, a search was performed in "all fields" and "all years" in that journal for "participatory epidemiology". It produced the following three additional hits (Tschakert et al., 2016; Craddock and Hinchliffe, 2015; Leach and Scoones, 2013). Through the author lists of these seven publications and through internet searches, we identified the academic background of all authors. Table 1 presents the results of the search.

Table 1: *Academic background of authors of journal papers in participatory epidemiology*

Reference	Academic discipline					Specific subjects
	Veterinary medicine/epidemiology	Other natural science	Edu-cation	Social science/humanities	Transdis-ciplinary	
Catley et al., 2009	5	3				Veterinary medicine, nutrition science and food policy, biotechnology
Catley et al., 2012	4					Veterinary medicine
Goraya et al., 2013		6				Parasitology, pharmaceutical science, clinical medicine and surgery, animal sciences, plant breeding and genetics
Leach & Scoones, 2013				1	1	Geography/anthropology, agricultural ecology and development studies
Coffin et al., 2015	3	1	1			Veterinary medicine, epidemiology, biology, education
Craddock & Hinchliffe, 2015				2		Women's studies, human geography
Tschakert et al., 2016		1	1	3	1	Geography, anthropology, transdisciplinary research, ecology, gender studies, development studies, human ecology, adult education
Total no. of authors per discipline.	12	11	2	6	2	

Although the small sample made it impossible to identify any significant trends, as seen in Table 1, this brief overview indicated that to date, social science researchers have been involved in PE only to a minor extent. Of the seven publications claiming to engage with social science in some regard (Coffin et al., 2015; Catley et al., 2009; Catley et al., 2012; Goraya et al., 2013; Craddock and Hinchliffe, 2015; Tschakert et al., 2016; Leach and Scoones, 2013), only three have social scientists among their authors (Leach and Scoones, 2013; Tschakert et al., 2016; Craddock and Hinchliffe, 2015), or four if educational researchers are included (Coffin et al., 2015), which could be viewed as being of high relevance for the development of PE. It should be acknowledged that many of the authors of the publications listed above, although not having an academic background in the social sciences, still have documented long-term practical experience of participatory work with animal owners and farmers. This is of high value for the possibility to develop PE as a useful approach in practice. However, it can be claimed that the fact that so few authors in the PE literature have a background in social science research has resulted in lack of acknowledgement in that literature of the significant critique and scrutiny of participatory research described above. It is possible that this situation is starting to change, as the literature sample indicates more social science involvement since 2013 (Table 1). In order to identify the

topics discussed by social scientists engaging in PE, we analysed the four publications with social scientists as authors in more detail. We found that Leach and Scoones (2013), Craddock and Hinchliffe (2015) and Tschakert et al. (2016), although mentioning PE, in fact do not focus empirically on PE in their studies. Nevertheless, these studies provide important indications on how PE could be improved, drawing insights from the social sciences.

Leach and Scoones (2013) focus on different ways of modelling zoonotic diseases. They mention PE and suggest that the most common reason for institutional interest in using PE is that there are no other data available on a particular disease. As stated above, this may be one reason why PE has mainly been used in developing country contexts (Catley et al., 2012). Leach and Scoones (2013) argue, however, that it is important to use PE also in contexts where data exist, as ethnographically-grounded approaches in general and PE in particular can contribute new framings of a disease that complement scientific framings and, by including local customary practices and perspectives, may facilitate local acceptance of interventions.

Craddock and Hinchliffe (2015) focus on what social science can contribute to the term and associated agenda of “one world, one health”. Those authors argue that despite the acknowledgement in the academ-

ic community about the relevance of engaging social scientists in the “one world, one health” programme, this has achieved very limited success so far. They list four themes where they believe social scientists could contribute to research on ‘one health’:

1. By highlighting the effects that uneven power relations (within local communities, between scientists, health workers and farmers) might have on the distribution of risks resulting from particular disease outbreaks and choices of interventions.
2. By questioning how problems of particular disease and disease outbreaks are framed and the effect that this has on different groups in society.
3. By analysing the effects of various human/non-human relations and by making these connections empirically clearer and theoretically more specific.
4. By bringing a critical eye to bear on whether and how local people’s knowledge is actually taken into account in contemporary veterinary research and by increasing understanding about why and how particular diseases are relevant in particular regions.

These suggestions by [Craddock and Hinchliffe \(2015\)](#) for making social science contributions to the ‘one world, one health’ agenda could be extrapolated to the development of PE, making it increasingly relevant to the contexts of marginalised smallholders.

While mentioning PE, [Tschakert et al. \(2016\)](#), like [Craddock and Hinchliffe \(2015\)](#) and [Leach and Scoones \(2013\)](#), in fact do not discuss it per se. [Tschakert et al. \(2016\)](#) do not even focus on an animal disease, but on a disease affecting humans (Buruli ulcer). Nevertheless, lessons for PE can be learned from their work. They draw on [Haraway’s \(1988\)](#) concept of “situated knowledge” and the claim that all knowledge, including scientific knowledge, is situated and partial, in order to show that inclusion of local accounts *e.g.* of connections between disease outbreaks and other local social and environmental factors is of key importance for identifying variables that are likely to be relevant for successful local intervention and for prioritising intervention measures.

The only empirically based study using PE in the literature sample is that by [Coffin et al. \(2015\)](#). It is also the only study of the seven that is not (co)authored

by a social scientist (although including a researcher in education). [Coffin et al. \(2015\)](#) present a PE study of anthrax management in western Uganda and show that social pressures, poverty-related constraints and lack of health and veterinary infrastructure were more important for farmers’ response to the disease than their knowledge about anthrax. Findings like this are important in killing the persistent myth that farmers will do what the authorities expect them to do if they have the correct knowledge. The presence of this myth in much conventional veterinary research is also pointed out by [Craddock and Hinchliffe \(2015\)](#), who emphasise that without participation on equal grounds by social science researchers in the ‘one health’ research programme, there is a significant risk that social science knowledge will only be added on to fixed research agendas for the sake of disseminating scientific knowledge.

Conclusion

In the short review of papers presented above, we did not find a single empirical study using PE performed by a team that included social scientists. However, the review also showed that by looking around the fringes of the PE literature, it is possible to find many publications of high relevance in furthering PE as a multidisciplinary and participatory methodology and approach ([Leach and Scoones, 2013](#); [Tschakert et al., 2016](#); [Craddock and Hinchliffe, 2015](#); [Coffin et al., 2015](#)). The fact that the engagement with social sciences within PE so far is virtually non-existent, in combination with the claim that PE has so far mainly paid lip service, without any actual local participation ([Catley et al., 2012](#)), makes it timely to consider what the social sciences can actually contribute within PE. This paper is a first step in this regard. Based on the findings presented, we suggest that research projects need to be created where social scientists and researchers in veterinary medicine work closely together in the field and continue to develop the PE methodology together, drawing on insights from the social sciences and from scrutiny of local empirical accounts. Lessons learned from participatory research ([Jacobson, 2013](#); [Calderon, 2013](#)) and from recent social science engagement with PE ([Leach and Scoones, 2013](#); [Tschakert et al., 2016](#); [Craddock and Hinchliffe, 2015](#); [Coffin et al., 2015](#)) indicate that this can have a significant impact on the validity and local relevance of PE research results in the future. It could help us see (and ultimately address) how power dynamics with-

in local communities, as well as between smallholders and authorities, affect disease impact and control (Craddock and Hinchliffe, 2015), and bring important clarity to the multiple factors influencing human behaviour and habits crucial for disease control, while avoiding over-simplistic explanation models citing “lack of knowledge” as the main cause of continuous disease transmission (Coffin et al., 2015; Chenais et al., 2015b; Tschakert et al., 2016).

According to FAO (2013), the major challenge in achieving control of PPR is not technical, but instead lies in understanding and meeting the specific needs of sheep and goat producers in affected countries. This is supported by research on eradication of rinderpest virus, where it has been acknowledged that a clear understanding of the institutional constraints, the specific needs of targeted animal owners and power relations was of the essence for ultimately achieving full eradication (Mariner et al., 2012). In the regions where PPR is now spreading, the mainly extensive sheep and goat production, mostly involving poor, marginalised groups, including pastoralists, women and young people, necessitates low-cost control options that are fully adapted to the local situation and willingly accepted by end users, as has been proposed for other diseases in similar settings (FAO, 2013). The review presented here suggests that in order to establish sustainable, locally relevant control of PPR, a better understanding of how affected people perceive and deal with animal disease in general, and PPR in particular, is needed. Likewise, more knowledge is needed on the effects of power dynamics within local communities, and between smallholders and authorities, on smallholder actions to control disease and on the role of small ruminants for people’s livelihoods in regions affected or threatened by PPR. The present review also indicates that adopting a PE approach inclusive of social science competence for studying and implementing PPR control strategies could make it possible not only to empower resource-constrained animal owners, but also to extract data that would be difficult to acquire by conventional methods, and that in fact would be more accurate.

In summary, a PE approach engaging social science to study the impacts of PPR, its control and the community responses to the disease could produce new insights not possible to obtain through conventional veterinary science methods. As PPR is likely to have its most severe impacts on marginalised smallhold-

ers, drawing lessons from social science research into PRA with regard to reaching the poorest is highly relevant. By drawing on and developing PE through true engagement with affected groups, future research on the control of PPR can become more relevant locally. This is crucial for attracting and retaining commitment among the smallholder farmers concerned, which in turn is fundamental for achieving the goal of the FAO programme for control and eradication of PPR by 2030.

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Conflict of Interest

The authors declare that there is no conflict of interests regarding the publication of this article.

Authors’ Contributions

All authors contributed to writing the text. Klara Fischer performed the review of social science research on participatory epidemiology and led the writing of the paper. Erika Chenais contributed knowledge and text on participatory epidemiology and PPR. Emeli Torsson and Jonas Wensman contributed knowledge and text on PPR.

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