

Power, participation and their problems: A consideration of power dynamics in the use of participatory epidemiology for one health and zoonoses research

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ABSTRACT

The use of Participatory Epidemiology in veterinary research intends to include livestock keepers and other local stakeholders in research processes and the development of solutions to animal health problems, including potentially zoonotic diseases. It can also be an attempt to bring some of the methods and insights of social science into a discipline largely shaped by natural science methods and ways of seeing the world. The introduction of participatory methodologies to veterinary epidemiology and disease surveillance follows a wider movement in development thinking, questioning the top-down nature of much post-second world war development efforts directed from the Global North towards the Global South. In the best cases, participatory methods can help to empower the poor and marginalised to participate in and have some control over research and interventions which affect them. Compiled from experience in multi-disciplinary One Health projects, this paper briefly traces the rise of participatory epidemiology before examining some of the limitations observed in its implementation and steps that might be taken to alleviate the problems observed. The three areas in which the operationalisation of Participatory Epidemiology in veterinary and One Health research could be improved are identified as: broadening the focus of engagement with communities beyond quantitative data extraction; taking note of the wider power structures in which research takes place, and questioning who speaks for a community when participatory methods are used. In particular, the focus falls on how researchers from different disciplines, including veterinary medicine and the social sciences, can work together to ensure that participatory epidemiology is employed in such a way that it improves the quality of life of both people and animals around the world.

Keywords:

Participatory epidemiology

Zoonoses

Infectious disease control

Power relationship

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Introduction

The use of Participatory Epidemiology (PE) in veterinary research intends to include livestock keepers and other local stakeholders in research processes and the development of solutions to animal health problems, including potentially zoonotic diseases. It can also be an attempt to bring some of the methods and insights associated with the social sciences into a discipline largely shaped by natural science methods and ways of seeing the world. Written by a group of social scientists working on projects which focus on the prevention and control of zoonoses, this paper traces the introduction of participatory methods to the wider development landscape and their operationalisation as PE in veterinary research, before detailing some of the barriers to transformative application of participatory methods observed in our own work on veterinary projects. The final section of the paper suggests ways in which social scientists and veterinary researchers might work together in the future to address some of these issues. We hope that our suggestions will help research and intervention activities better reflect the views of livestock keepers and those who live alongside them.

The rise of participatory approaches

While the concept of participation may only have been invoked in veterinary epidemiology relatively recently, it has a longer history in international development research and practice. The impetus for developing the participatory approach came from scholars such as Robert [Chambers \(1983\)](#), who advocated for alternatives to the modernist, topdown approaches characteristic of post-war international development efforts. These were focused around the transfer of expertise and technology from the 'developed' global North to the 'third world' with dominant stakeholders determining the priorities and goals according to their own interests and agendas ([Isidiho and Sabran, 2016](#)).

The assumption that the positivist perspective of western scientific disciplines, which have a tendency to see the world as a single incontrovertible reality ([Baum et al., 2006](#)), should be adopted in research and interventions seeking to improve the lives of the world's poor ran the risk of imposing 'one size fits all' technical solutions onto diverse contexts, cultures and challenges. It might also ignore the valuable knowledge of people who intimately know those contexts, cultures and challenges. As a result, it might fail to recognise and grapple with the political forces which act on people's lives and shape their experience of and relationship with poverty, disaster or disease (e.g. [Ferguson, 1994](#); [Moore, 2015](#)). Despite the establishment of sustained campaigns of international development pursued through the Bretton Woods institutions (e.g. the UN and the IMF) and the implementation of technical solutions, levels of poverty across the world did not decrease ([Blackburn et al., 2000](#)). Such forms of development were subject to much criticism, particularly from "post-development" writers such as Arturo [Escobar \(1995\)](#) and Wolfgang [Sachs \(1992\)](#), who condemned the top-down imposition of western scientific approaches for devaluing and even destroying indigenous knowledges and ways of being and for reinforcing global, often colonial, hierarchies of power.

A growing number of authors and practitioners insisted that a new approach to

development was required ([Blackburn et al., 2000](#); [Cornwall, 2006](#)), and that it should be applied to both academic re- search and development interventions. Indeed, it was also posited that the line between research and intervention/action should be blurred, with the former aiming towards achieving the latter, responding to the contributions made by participants ([Baum et al., 2006](#)). The implication was that one-size-fits-all development should be replaced with locally- relevant solutions and that, for this to happen, the people who were the ‘targets’, ‘beneficiaries’ or ‘subjects’ of development should participate in (or, in more radical variations, take charge of) project design and implementation, and/or of the framing and definition of problems and questions used for data collection. Simultaneously, there was a move to appreciate the value of local and indigenous knowledge and how such knowledge might be used in conjunction with ‘western knowledge’ to construct effective responses (e.g. [Nyong et al., 2007](#); [de Sousa Santo, 2014](#); [de Sousa Santos, 2018](#)). Thus, the initial drive for participatory approaches was one that challenged the status quo of the existing development industry, recognised and valued local knowledges, acknowledged the limitations of technical solutions, and required collaboration and co-operation, with the people who were the ‘objects’ of development becoming active partners. This shift was put forward as a potential route out of the development impasse. However, the introduction of participatory methodologies to development has also received criticism for merely defining itself in opposition to a previous ‘totalizing’ paradigm for development research and intervention. This did not allow for diverse voices to be represented and “overlooked and marginalised ‘pluriversality’” ([Klein and Morreo, 2019](#), pg. 4), without properly defining its own methods and how they should be operationalised ([Campbell, 2002](#)).

Mainstreaming ‘participation’ and its challenges

Over time, the participatory approach, or at least the term ‘participation’ and its cognates, has been mainstreamed and, in some ways, co-opted by major players – including governments, international and national non-governmental organisations and charities – in the development apparatus. As early as 1969, Arnstein pointed out that, there is “a critical difference between going through the empty ritual of participation and having the real power needed to affect the outcome of the process.” [Arnstein \(1969\)](#) constructed a theoretical ‘Ladder of Participation’, now commonly referenced in development planning. The ‘ladder’ ascends from the first rung: ‘non-participatory’ engagements with communities, to “enabling powerholders to ‘educate’ and ‘cure’ participants”, through ‘tokenism’, to genuine ‘participation’, where “have-not citizens obtain the majority of decision-making seats, or full managerial power”. This typology is indicative of the variety of approaches that can adopt the label of ‘participation’. It is what Corn- wall terms an “infinitely malleable term” (2006; pg 63). Today, both academic researchers and development practitioners are often required to show the participatory nature of their prospective projects in order to obtain funding. Again, the concern shown by funders for elevating the voices of local people is laudable. However, there is a danger that if adequate time and resources are not allocated to developing these methods and activities, ‘participation’ becomes little more than a ‘buzzword’ ([Cornwall, 2007](#)) employed as part of a box- ticking exercise. We argue that this problem emerges from participation being invoked without careful consideration of how its implementation interacts with the delicate power relationships that exist in any society. To conceptualise and discuss power in this paper, we look to Gaventa’s (2006) scholarship – specifically his ‘power cube’ framework. Gaventa (2006) posits three dimensions of power: forms, spaces and levels ([Fig. 1](#)).

Forms of power

According to Gaventa (2006), power can take 1) visible, 2) hidden, and 3) invisible forms. Visible power is identifiable and observable political power such as that embodied in laws, governments and authority figures, which grants individuals and institutions the ability to make decisions that affect the lives of others. Hidden power refers to power that influences and sets agendas by suppressing or elevating certain narratives and discourses. Invisible power is insidious power that influences how individuals think about their own agency, such as social norms and cultural values.

Spaces of power

These different forms of power are exercised in 1) closed, 2) invited, or 3) claimed spaces. Many decisions are made in closed spaces where actors (often holding visible power) do not open the decision-making process to wider stakeholder groups. When outside stakeholders, including those who usually lack political voices, are invited to participate in decision making, invited spaces emerge. In claimed spaces, less powerful actors may demand their voices to be heard by powerful actors, claiming their place in decision making.

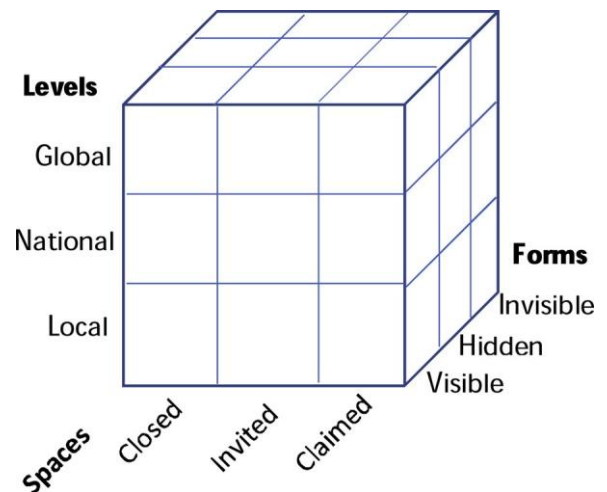


Fig. 1. The power cube. Source: Gaventa (2006).

Levels of power

Forms and spaces of power may reside at different levels: global, national and local. While certain actors are considered powerful at the local level, these very actors may be silenced by power imbalance at the national and/or global level and find themselves relatively powerless. Gaventa's power cube framework provides us with a helpful lens through which to view power imbalances and their influence on PE. For instance, who is it that participates in participatory research? While the notion of 'community engagement' is frequently invoked in both re- search projects and intervention, any 'community' consists of individuals with competing interests shaped by class, gender or ethnicity ([Briggs and Sharp, 2004](#)). The complexities of social relationships, power and politics mean that any 'community' invited by facilitators of Participatory Methodologies is unlikely to represent this diversity of experiences and interests. Indeed, as [Grünenfelder and Schurr \(2015\)](#), drawing on [Crenshaw \(1991\)](#) concept of intersectionality state, efforts to ensure representation and participation in development must move beyond a focus on broadly defined identities that are often assumed to be universal and distinct, e.g. woman, illiterate. As a result, well-intentioned 'community engagement' is unlikely to represent the views of all people in a place as a community is heterogeneous and unique ([Hillery, 1955](#); [Amit and Rapport, 2002](#)). Often, voices excluded from community engagement come from those members who lack voices and influence in other areas of life (e.g. [Wilkinson et al., 2017](#)). Thus, when applied uncritically, participatory approaches can reinforce existing power imbalances ([Arnstein, 1969](#)) rather than opening up discussion and empowering the marginalised. Conversely, ethical issues arise when involving powerless and marginalised people in participatory approaches that require extensive time commitments from participants. Without adequate remuneration, such commitments can lead to the over-burdening of already heavily burdened people with limited means, particularly women (e.g. [Cooke and Kothari, 2001](#); [Mayoux, 1995](#); [Omata, 2019](#)).

Summary and our contribution

The rise of PE should be understood within this broader context of longstanding critique and debate surrounding power relationships and the resulting challenges of participatory approaches in development research and practice. Few would now challenge the importance of including the voices of populations in the design of development pro- jects that will affect them or in research about them. However, achieving more appropriate and more inclusive outcomes requires attentiveness to issues of power, voice and access to resources. It is this challenge that we address in this paper from the perspective of social scientists, including anthropologists, geographers and economists, en- gaged in interdisciplinary One Health projects.

In the following section, we first present how the concept of participation has been incorporated into veterinary epidemiology and dis- ease surveillance, and how this is currently theorised and implemented, resulting in the methodologies collectively known as PE. Then, we discuss challenges in employing PE to reflect local people's voices and concerns in veterinary epidemiology, drawing from documentation in the literature as well as our experiences from the Zoonoses and Emerging Livestock Systems (ZELS) programmes¹. In the following section, we suggest ways to improve

¹ The ZELS programme is a joint research initiative between the UK's Department for International Development, the Biotechnology and Biological Sciences, Economic and Social

the current ways in which PE is operationalised, reflecting the challenges identified, before concluding.

Participatory approaches in the context of veterinary epidemiology

PE recognises that people dependent on livestock for their livelihoods not only have significant understanding of livestock production, but also of the epidemiology of endemic diseases (FAO, 2000; Mariner et al., 2014) in their specific context. The use of local knowledge through participatory methods supports the adoption of a risk-based approach, increasing consideration of the roles local culture and social relationships play in disease transmission (Mariner et al., 2014). Participatory modelling may reveal risk factors originating from social roles and cultural practices and enhancing epidemiological models by providing insights into local contexts (Scoones et al., 2017). There are examples of local people predicting infectious disease outbreaks, understanding origin of diseases in livestock and taking precautionary measures (FAO, 2000).

Jost et al. (2007) trace the development of veterinary PE from the 1970s, describing how pastoralist communities with very limited access to western veterinary services and expertise “have very rich and detailed knowledge about the animals they keep...infectious and zoonotic diseases.” The use of PE methods in the Global Rinderpest Eradication Programme is cited as a key moment in the development of veterinary PE methods, where they were used in combination with training Community Animal Health Workers (CAHW) to mitigate accessibility issues faced by vaccination campaigns in remote locations (Mariner et al., 2014). ‘Traditional information networks’ were also employed in ‘disease searching’, influencing the formulation of an important subset of PE: Participatory Disease Surveillance (PDS). Nonetheless, the advancement of community empowerment within wider development structures was instrumental to the more rigorous implementation of participatory methods as part of epidemiological responses (FAO, 2000).

Jost et al. (2007) list the following as examples of PE methods: semi-structured interviewing, focus-group discussions, ranking and scoring disease observations, including simple ranking, pairwise ranking and proportional piling, a variety of visualisation (e.g. mapping and modelling) and diagramming techniques (e.g. seasonal calendars and historical timelines). When Allepuz et al. (2017) reviewed PE practices in animal health between 1980 and 2015, they found that most activities primarily focussed on disease surveillance, followed by survey and prioritization and lastly control, and that commonly used tools included mapping, scoring and prioritizing areas within research projects (Allepuz et al., 2017). For example, in PDS, the researcher connects with local livestock keepers, farmers and other relevant key informants to discuss their perception on local diseases through interviews, ranking and scoring and visualization using calendars, mapping and timelines (Ameri et al., 2009). Community representatives are asked to name common symptoms which may be attributable to zoonotic disease and rank these according to their impact on human and animal health and their prevalence in domestic animals (Okello et al., 2011).

Sciences, Medical Research and Natural Environment Research Councils, as well as the Defence Science and Technology Laboratory. Since 2012, ZELS has funded 11 multidisciplinary projects in low- and middle-income countries with emerging livestock systems which are considered to be at risk from zoonotic diseases.

However, [Catley et al. \(2012\)](#) suggest that PE should involve communities in 'defining and prioritizing veterinary-related problems' from the outset. More systematic PE methods which include communities at earlier stages of research projects would enhance locally appropriate, acceptable and feasible disease control options ([Catley et al., 2001](#)). Increasingly, participatory methods are being used more systematically, triangulated and combined with quantitative data ([Catley et al., 2001](#)). Local perspectives and priorities play an increasing role in guiding the study ([Chenais and Fischer, 2018](#)). Furthermore, there is an increased focus on inclusion of participatory approaches within veterinary teaching curricula and the use of modern technology, e.g. voluntary participants providing health related information for disease surveillance via digital media and platforms, which may inform contextualised practice and policy development ([Catley et al., 2001](#); [Christaki, 2015](#); [Mtema et al., 2016](#)).

Analysis: how PE is operationalised

In this section, we move from the theoretical to the more practical, analysing the ways in which PE is currently operationalised in epidemiology and veterinary sciences and identifying the potential challenges associated with making PE 'truly' participatory. Drawing on evidence from social science research that has examined how the PE approach might play out in practice, we first assess and problematise how local people are assumed to interact with researchers through the design of PE approaches. We then analyse the broader framing of the One Health and zoonoses research agenda and priorities, which can impede active participation by local people in research programmes. Finally, we demonstrate and problematise how existing power dynamics shapes the implementation of projects and PE and ignoring these could obscure the voices of poor, and often powerless, people.

Operationalising PE: extracting data instead of listening to local people's voices

Much current operationalisation of PE stops short of reflecting local people's views and priorities, as participatory research tends often to be seen simply as a tool to extract data on disease dynamics from local people ([Catley et al., 2012](#)). This is likely due to veterinary PE's roots being in Rapid Rural Appraisal (RRA), as opposed to in Participatory Rural Appraisal (PRA) ([Fischer and Chenais, 2019](#)). According to [Chambers \(1994\)](#), RRA was developed and praised as an alternative to structured surveys that were costly, time-intensive and did not produce reliable (quantitative) data. As a result, the purpose of RRA is to extract useful data in a rapid and cost-effective manner, especially when a crisis such as a disease outbreak was in progress. On the other hand, PRA allows researchers and extension workers to visit communities and explore issues and learning opportunities that matter to members of those communities in a more open-ended way, theoretically without preconceived ideas of what they will find. It is therefore understandable that PE in veterinary science, which was derived from RRA, continues to focus on the collection of quantitative or semi-quantitative data. What this means is that veterinary PE tends to approach local knowledges with a set of pre-defined questions to obtain data from local communities which is thought to be scientifically relevant, i.e. verifiable and often quantitative. In particular, natural scientists tend to view qualitative data as useful only in so far as it can inform quantitative epidemiological models ([Grant et al., 2016](#)). When teams are

led by natural scientists with expertise in a particular disease or pathogen, their focus is also, understandably, likely to fall on that disease or pathogen, even if it is not a priority for local people and their animals.

Under the current PE practices, in Gaventa's (2006) terms, local people are invited to spaces of power in order to share their knowledge with a pre-defined objective. Consequently, their participation may not effectively address those veterinary-related problems that matter most to local people ([Fischer and Chenais, 2019](#)). Often, the voices of 'the community', represented by chosen leaders, are reflected in PE in the form of their understanding of symptoms related to particular zoonotic diseases and their ranking of these symptoms according to impact and prevalence ([Okello et al., 2011](#)).

Researchers conducting PE exercises commonly use methods such as participatory mapping, proportional piling, key informant interviews, ranking and scoring, and visualization through calendars ([Ameri et al., 2009](#); [Coffin et al., 2015](#)). These methods may be classified as passive ([Isidiho and Sabran, 2016](#)) ways for local people to participate in research activities: where participants respond to pre-defined questions and prompts from researchers and provide information on research topics, defined in protocols designed by outsider researchers. This contrasts with more active forms of participation which integrate participants within the design, planning, implementation and monitoring protocols of a research project ([Isidiho and Sabran, 2016](#)). 'Truly' participatory approaches would recognise the agency of community members to identify and/or refine methods that are appropriate to their context ([Chandler et al., 2013](#)) and take account of any locally relevant social differences that might bear on how disease impacts are distributed and experienced.

In addition to the ethical concerns associated with extracting information from people without proper explanation of a project or a plan for continued participation ([Kashurha, 2019](#); [Omata, 2019](#)), when the concerns of communities are not well thought through, there is a risk that the quality of that data will be compromised. For example, asking livestock keepers and/or CAHWs to report suspected and confirmed incidents of disease through PDS is unlikely to prove useful to epidemiologists unless they have established that reporting such cases poses no harm to participants. When the greatest threat to livelihoods and sometimes to the nutritional status of a family ([Lockerbie and Herring, 2009](#)) is the culling of animals without compensation in order to contain a disease, people are unlikely to report. If ranking, prioritisation and participatory mapping methods are used to construct lists of the diseases in a location and the veterinary services available, without further qualitative enquiry about what these diseases mean for people's lives, or whether veterinary services and resources are easily and equally accessible, there is a risk of missing these crucial insights which could help in the development of more appropriate and effective surveillance systems.

The wider research contexts that can impede truly participatory PE

One Health research programmes exist in the wider context of the global health agenda ([Leach and Dry, 2010](#)). In this context, research priorities are often set by international institutions and agencies and/or the governments of 'donor countries' funding global One Health research programmes. As a result, implementation of One Health research programmes tends to be wrapped up in the wider securitisation agenda, focusing on pathogens that threaten the 'international community', economic growth

and development, and/or may further international scientific knowledge ([Dry, 2008](#); [Perry et al., 2013](#)). Addressing the needs of poor people may not be the top priority in these agendas. In terms of Gaventa's (2006) model, this issue can be understood in relation to the level dimension of the power cube.

While One Health was designed to integrate various disciplines to tackle complex global challenges in health and can lead to more equitable outcomes than more narrowly-focused approaches (see [Halliday et al., 2017](#)), some veterinary scientists saw the attention being paid to sporadic outbreaks of zoonotic diseases as an opportunity to enhance the role of veterinary science in global public health and to, quite legitimately, access a proportion of the funds attached to these challenges ([Valeix, 2018](#)). As a result, One Health research tends to emphasise specific (zoonotic) diseases – such as Avian Influenza and Swine Flu – that have potential for global pandemic, which were donor priorities ([Galaz et al., 2015](#)). As most projects and interventions are funded and, at least partially, defined by the aid agencies of donor countries in the global North, sometimes in partnership with the national government of the country in which the project is operating, it is unsurprising that such projects seek to achieve the aims of the countries from which they are funded and planned. Although One Health has been praised for providing an innovative and cost-effective solution to problems in human, animal and environmental health (e.g. [Zinsstag et al., 2015](#); [Destoumieux-Garzon et al., 2018](#); [WHO, 2017](#)), it is a capacious concept. It is much used but can also be shaped to fit and support the status quo ([Craddock and Hinchliffe, 2015](#)). This means that the same power structures and relationships which influence all other research also shape the way in which One Health research and interventions are carried out. In other words, while researchers from different disciplines may be brought into a project, pre-existing biases and ideas of superiority and inferiority are likely to persist.

Unfortunately, the focus on high profile zoonoses may also act as a limitation to developing truly participatory PE. In our experiences through the ZELS programme, priority diseases according to the international communities are often far from the top of farmers' and local people's list of animal health priorities in the global South (e.g. endemic pig-borne zoonoses in Myanmar, bovine tuberculosis in Ethiopia). In addition, the current disease-specific approaches to understanding disease burdens contrasts with the epidemiological reality faced by local people, which are characterised by conditions of comorbidity (see [Chenais and Fischer \(2018\)](#) for an example from Uganda). In other words, simply employing participatory methods to understand the epidemiology of specific diseases that are not perceived to be important (enough) by local people is unlikely to improve One Health and mitigate poverty.

In addition, the ways in which funding applications are developed and project activities are implemented make the participation of communities in research project development extremely difficult. For instance, all ZELS projects were led by biomedical scientists, many of whom are experts on particular diseases. In such cases, it is difficult for PE to be implemented at the initial phase of the project and the findings used to challenge the narrative that the diseases to be studied are of critical importance in the eyes of local people. For example, [Ducrottoy et al. \(2016\)](#) describe how their work on brucellosis interventions in Northern Nigeria illuminated 'bias about the "backwards" Fulani', as well as a lack of engagement with communities' actual concerns. The community was believed to employ 'risky practices' in their care

of animals. Therefore, political and scientific authorities assumed that the animals were likely to be infected as a result. Once it was established through epidemiological surveys, biological sampling and focus group discussions, that brucellosis was not prevalent within the study site, it was too late to change the focus of the project either to a different location, or to a disease which was of more concern to the community with whom they were working. When focus-group discussions and interviews were held with local people once the project was underway, they were able to tell researchers, through discussing symptoms, that brucellosis was far from the top of the list of diseases affecting their cattle and consequently their livelihoods.

An alternative to this way of working is exemplified in the Dynamic Drivers of Disease in Africa Consortium project, which ran from 2012 to 2015. This project, while focused on particular diseases in a number of different sub-Saharan African countries, focused on establishing the factors that led to the emergence and impact of zoonotic disease, using citizen science alongside traditional epidemiological mapping. A somewhat similar approach is being taken by the Wellcome Trust-funded Centre for Cultures and Environments of Health at the University of Exeter, which is founded on the recognition that the world's health "challenges are often 'more than biomedical' in complexion, being social, cultural and environmental in terms of their key drivers and determinants..." ([Hinchliffe, Jackson et al. 2018](#), pg. 1).

Participatory approaches which go beyond the extraction of quantifiable data may need to be subject to detailed discussion between natural scientists and social scientists. However, such exercises take time and some authors of this paper have found it difficult to allocate an explorative phase at the beginning of our ZELS projects. This challenge was prominent not only between social and natural scientists but also among different disciplines of social sciences. Some authors were brought into our corresponding projects by veterinary colleagues in places where they had existing partnerships with local biological researchers and institutions. As a result, social scientists were sometimes unable to spend the significant amount of time necessary to adequately scope and build relationships with local social scientist partners. Also, the difference between economists and other social scientists who are experts in participation posed challenges in planning participatory research. Launching PE activities takes time; time which is not readily available when project cycles are short.

Power dynamics within 'the community': identifying voices elevated and silenced

In this sub-section, we argue for the need to move beyond defining the success of PE approaches based on the level to which the broadly defined 'community' is engaged with. Instead, PE needs to help reveal the complexity of levels of engagement, such as the necessity to also consider power dynamics which inevitably exist within any 'community' ([Grünenfelder and Schurr, 2015](#)). External power dynamics – the hidden power – may determine how local authorities and academic partners direct foreign researchers towards particular communities and locations, which see some voices elevated and trusted, while others are silenced and/or treated with suspicion. 'Communities' that are selected as study focal points are likely chosen as a result of complex socio-political dynamics. Such decisions are likely to be driven by unconscious bias and may be driven by a genuine desire to assist populations considered to be particularly at risk without critical assessment of assumptions. Such

assumptions can be held both by researchers working in a country far from their own (global level), or by those working in their own home country (national level).

Such socio-political dynamics may be more apparent to social scientists – particularly anthropologists, regional studies researchers, sociologists and geographers – who are accustomed to considering issues of power in their work, and/or to those who have a large amount of experience working in a particular place and/or with frequently marginalised groups (e.g. pastoralists, inhabitants of informal settlements etc.). However, for those researchers who may not spend significant amount of time in study areas, it can be easy to overlook the socio-political complexity, heterogeneity and power dynamics that surround the laboratories and meeting rooms through which they move. The direct involvement of national governments and their research agencies in choosing research sites and veterinary health issues to focus on, is often related to their prioritisation of resource spending and attitude towards livestock owners. This places all researchers in a difficult position. It is, of course, the responsibility of the researcher to create as accurate a picture as possible of what is happening within their research sites and to address relevant issues. However, this has to be done without alienating, or even embarrassing, partners, particularly governments whose cooperation or at least permission is usually essential for any work to be done. Such issues do not only apply to researchers working across borders in countries wherein histories of colonialism sculpt pervasive inequalities and complex relationships, but also to those working in their own home country: vast distances often exist between academic elites and ‘researched’ communities.

In order to make research locally relevant and to fulfil funders’ aims of capacity building, projects developed in the global North are increasingly designed and carried out in collaboration with academic partners from the global South on which they focus. Projects may include targets for capacity building, such as the training of researchers in the project country, built in log frames and theories of change. However, political and academic elites in study countries may have as little understanding and experience of the lives of their poorest compatriots as academics in the global North. ‘Local’ researchers selected for international projects are often educated in the West or in western institutions and may have come to denigrate the knowledge and ways of being of poor and marginalised people. As a result, officials working at the local level, heads of farmer cooperatives, community leaders and community health workers may feel alienated from the worlds of western academia and national administrative processes. This is an example of invisible forms of power, inhibiting the scope of true participation from local people. Therefore, working with southern partners without understanding these dynamics may be at risk of being ineffective in shifting away from ‘western norms’ of development with the aim of engendering genuine participation.

Concrete steps by which natural and social scientists can work together to improve PE practice

In a complex world populated by institutions, governments and people with differing levels of power and privilege, achieving fairness and equality is challenging. Arguably it is an impossible challenge, for which ‘participatory methodologies’ alone cannot act as a silver bullet. However, we propose that there are some steps that researchers and funders might take towards more effective applications of PE to improve lives of people and animals. Many of these steps begin with the recognition and naming of

power relations and seeking to identify and engage with the voices that are not currently being heard or responded to.

Approaching local knowledges differently

One challenge identified above is how researchers approach local people and their knowledges. Although PE intends to recognise local people's knowledge as central to understanding disease dynamics and ways to control diseases, research and interventions tend to be directed towards identifying mistakes in local people's knowledge, understanding and behaviours and then 'correcting' these mistaken ideas to change risky behaviours and 'harmful cultural practices'. Yet, the wealth of social science research shows that people's behaviours do not change easily due to the complex set of incentives, constraints, risks and perceptions from which these behaviours emerge ([Leach, 2015](#); [Thys et al., 2016](#)). Such approaches also assume the superiority of globalised (western) knowledge and solutions, which may not be equally appropriate to diverse local contexts. Social science research welcomes plurality and aims at lifting out diversity of opinion, without seeing this diversity as a flaw in data. At its best, this can translate into a willingness to understand and work with the cultural logics and practices that are salient in specific historical, political and economic contexts and realities and a willingness to consider alternative responses to problems. Such an approach offers a pointer towards an approach to PE that strives towards equality, considering varying understandings of disease, ways of being and livelihoods strategies, including those based in 'scientific/technical expertise', on a more equal footing.

Local experience and knowledge in the face of disease are powerful tools to combat diseases, [Parker et al. \(2019a,b\)](#) documented a striking case of Ebola response and 'community engagement' in Sierra Leone. In the village of Mathaineh, people rejected measures mandated by authority figures identified by international agencies and the national government. The people knew from previous experience that the official Ebola response was unlikely to save their loved ones. Instead, they chose to act on the information and experience they had from other disease outbreaks and treat infected people locally. In these isolated places, patients were appropriately cared for while those caring for them wore home-made protective gear. Many of those thought to be infected with Ebola survived ([Parker et al., 2019a](#)). Lay people saved lives by "drawing in strategies which had been used to contain and treat outbreaks in the past" and their "strategies were revised in the light of their own empirical observations about Ebola transmission" ([Parker et al., 2019a](#), pg. 448).

We argue that PE and wider One Health and zoonoses research should set research and impact agendas based on local people's understanding and perceptions of diseases and their livelihood realities, rather than focusing on changing their behaviours. Work within the ZELS programme highlighted that local people maintain certain behaviours as a result of their understandings of disease emergence, occurrence and consequences, the wider institutional contexts that often limit their agency to protect human and animal health, and their societal values ([Hodge et al., 2019](#)). A truly participatory PE should not assume that local people should change their behaviour, but rather ask how, given that people may behave in certain ways due to a complex nexus of conditions and power relations, can we best protect against disease and promote healthy animal-human interactions? It can also point at policy changes or interventions that might improve the structural conditions of people's lives, beyond a

focus on risks inherent to their realities. For instance, the above Ebola example demonstrates the effectiveness of solutions designed and implemented by local people because they know what responses are possible and realistic given their contexts of weak public health systems. Research can, for instance, address the strength and limitations of locally viable solutions instead of imposing solutions from 'outside'.

For this to work, however, trust between 'researcher' and 're-searched' must be earned and established. The example given by ([Parker et al., 2019a](#), pg. 447) indicates a lack of trust between local people and authorities due to past experiences of broken promises regarding the provision of infrastructure and schools. Similarly, attempts at PDS for Avian Influenza in Egypt show that livestock keepers feared that their animals would be slaughtered without compensation and veterinarians were concerned of being held responsible for AI cases that emerged after vaccination ([Peyre et al., 2009](#)). Clearly it is not the role of the researcher engaging in PE to raise expectations that these unsatisfactory outcomes will not occur, and it would be irresponsible for us to do so. However, we suggest that it is both sensible and moral for researchers to listen to and engage with these concerns, passing them up the chain when communicating with elite stakeholders and policy-makers (see also [Omata, 2019](#)). As Arnstein's ladder (1969) suggests, our use of participatory methodologies will be tokenistic if "the groundrules allow have-nots to advise but retain for the powerholders the continued right to decide" both what happens and what is communicated.

If the aim of veterinary and One Health research is to improve the quality of life of both animals and humans, we argue that allowing for social science framing of research questions will help to shift the focus away from specific pathogens and address pertinent issues for local people. This is because the social science disciplines are set up to consider issues of power and relationships between actors. Increasingly, zoonotic diseases have been found to emerge and travel between animals and humans as a result of complex interactions between animals, people and ecosystems ([Dzingirai et al., 2017](#)). Also, the way people understand, perceive and experience diseases influences policies and behaviour at the individual- and organizational levels ([Waldman et al., 2016](#)). In this context, seeking to understand and respond to disease dynamics and attempt to control them using purely disease-specific questions, defined before engaging with local people and observing local conditions, is unlikely to lead to lasting change.

Adjusting the framing of research questions in such a way requires a commitment to greater equality in interdisciplinary research collaborations - putting social sciences on an equal footing with the other disciplines involved in interdisciplinary research. The inclusion of social scientists within the ZELS projects has been appreciated and has led to innovative work. However, it is notable that none of these interdisciplinary projects was led by a social science principle investigator (PI). This suggests that social science is still considered as a supplementary part of the work, adding colour on to the concrete outline provided by the natural sciences. An example of an alternative approach can be seen in the recently launched GCRF One Health Poultry Hub, which factored in an iterative phase at the beginning of the re-search project so that social scientists could explore how poultry meat and eggs are produced and distributed in the study countries. The findings of this work will then be used to shape the work of epidemiologists and social scientists, who will jointly investigate the 'unknowns' identified by this preliminary work.

Of course, we have yet to see what insights such truly inter- and trans-disciplinary research projects will yield. However, this approach has already stimulated cross-disciplinary conversation about the relationship between pathogen emergence and genetic characteristics of various poultry breeds. This has challenged the assumption that ‘western’ style of intensification is desirable from public health perspective and urged researchers to look beyond the farms in improving farmers’ practices ([Hinchliffe, 2008](#)). We see this as an exciting opportunity for not only social scientists but also biological, physical and mathematical scientists to address research questions that matter for local people and develop ways that effectively improve their health and livelihoods with expertise in all disciplines.

Project activity planning: a phased approach that starts with PE

In order for such changes to take place, it is evident to us that re- searchers who are committed to employing PE will need to communicate the value of these methods to funders and partners, as well as lobbying for changes in the structure of project and funding cycles, which currently stand in the way of the effective implementation of PE. We propose that, for a project to focus on locally relevant research questions based on findings from PE, research projects should begin with a period of preliminary scoping using PE and other participatory methodologies. Including additional time and resources in grants for this purpose could also allow partnerships to be established between social and natural science researchers and institutions in different countries. This will allow time to establish good relationship within the research team, which may include researchers who have not worked together in the past. Also, the extra time will enable all research personnel to be introduced to the context in which they will be working. Allowing extra time for project planning processes also has the potential to improve some of the other issues we have identified with the current operationalisation of PE, including the building of trust ([N’simire, 2019](#)) and the identification of power dynamics within apparent ‘communities’.

While we appreciate that funders are likely to be reluctant to commit to a project where the focus is not necessarily clearly defined at the outset, it might be possible for funders to offer preliminary scoping grants, such as those recently offered by the National Lottery in the UK as part of their East Africa Disability Fund. The strategic grants were intended to be “flexible, focused on learning” and would “adapt over time as the context and issues evolve”. The grants were awarded to organisations, or consortia of organisations working in one of two ‘target countries’ on “aspects of economic empowerment, addressing root causes of vulnerability and poverty” ([National Lottery Community Fund, 2019](#)) among people with disabilities. Grants which encourage such iterative processes could enable PE methodologies to be utilised in ways that allow co-production of research and of any action in response to research findings.

We suggest that the participatory methods commonly identified as PE could be operationalised in a project planning and design process, with the data collected using these methods informing the formulation of research questions, goals and objectives of the project. Further meaningful participation could be achieved through involving local livestock keepers and other stakeholders in the collection, analysis and writing up of data. A research team could adopt this research model depending on skills and knowledge available among both communities and coordinating research facilitators, while the use of intermediary outcomes or sequencing of methods may support continued commitment of all partners ([Bach et al., 2017](#)).

In conducting PE at the initial stage, we may draw attention to facilitators' as well as participants' skills and expertise. In order to successfully implement comprehensive participatory approaches that ensure the relevance of data to all stakeholders involved, participants – i.e. facilitating researchers as well as participating community members – may require capacity building ([Allepuz et al., 2017](#); [Bach et al., 2017](#)). Working with an international project, particularly when the name of a famous university or scientist is attached, is extremely desirable for researchers in the South and is often crucial to promotion. This may mean that people whose skills are not best suited to participatory working are assigned to the projects because they are the 'best scientists', or because they are favoured by bureaucrats ([Baum et al., 2006](#)). Such training could include presentation, communication and community engagement skills ([Saylor et al., 2015](#)). It may also be helpful to recruit some researchers from disciplines where they are more likely to be accustomed to working with the public, e.g. nursing, social work. Researchers should also, where possible, be a heterogeneous community in terms of, for instance, gender, ethnicity and age.

In addition, the research team may consider a contextual training for all academics from the global North. Although the social scientists on the project may take notice of the political and historical context of the place they are working in, these dynamics may not be obvious to natural scientists. This could provide an opportunity for social scientists from the South to offer training to scientists – both social and natural – from the North.

Finally, researchers need to be mindful that many local people in areas thought to be at risk of disease outbreaks are over-researched, having been repeatedly visited by research teams often asking the same questions, without delivering tangible solutions to the problems affecting their lives on a daily basis ([Omata, 2019](#)). This issue is likely to become more common, as One Health becomes more of a global priority. Research projects need to address how communities could benefit from participating in the research. This could include training in research tools, technologies and models, as well as having their voices heard further up the policy-making chain. Designing research projects based on PE ensures that scientists address issues that are pertinent to local people. This should, at least, motivate scientists to bring the research outputs back to the communities. Funders may consider mandating such a feedback process to accelerate social and developmental impacts of research activities.

Conclusions

This paper critically examined the ways in which participatory epidemiology (PE) is currently practiced in the field of veterinary epidemiology and broader One Health and zoonoses research programmes. Drawing on evidence from the literature and our experiences through the ZELS programmes, we discussed three main challenges in making PE truly participatory. First, we highlighted that PE methods currently focus on obtaining (quantitatively) relevant and accurate information from local people. This emphasis on data extraction, we argued, limits the extent to which local people can define research priorities and find solutions that would be suitable for their contexts. Second, we analysed how disease priorities are set by the wider global health agenda and how international priorities are not always aligned with local people's priorities. Therefore, PE practiced in this context may not be relevant for local people who participate in various programmes. Third, we emphasised the need to recognise and, if

possible, address the power dynamics that exist within ‘the community’ and between community members and researchers. Ignoring the power relationships poses the risk of obscuring the voices of poor and marginalised people, which PE methods intended to reflect and address.

We suggest two ways to address these challenges. First, we urge researchers to approach local knowledges differently by incorporating social science framing of biological questions. More specifically, we argued that research projects should focus on asking questions that address the realities of local people and how they understand human and animal health. This can be done, for example, by framing biological challenges through social science lens to employ people-centred approaches. Researchers must assume that particular behaviours exist as a result of complex ecological, political, economic and social contexts, and ask ‘how can we, interdisciplinary scientists, help local people to best protect against disease and promote healthy animal-human-ecosystem interactions?’ Second, we suggest that the funding and re- search environments allow an iterative phase at the beginning of project implementation to allow ample time to inquire from community members what their disease priorities are. This will require individual projects to allocate an iterative phase at the beginning and/or funders to offer scoping grants, such as the National Lottery in the UK as part of their East Africa Disability Fund, to mandate an explorative approach to health problems.

We hope that these suggestions stimulate innovations in the inter- disciplinary research community to better reflect local people’s voices in the research we conduct and therefore accelerate the real-world impacts of research programmes. Asking locally relevant questions ought not (always) be a compromise in terms of disciplinary excellence. Instead, it should be an exciting opportunity to push the boundary of knowledge in all disciplines involved.

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