Participatory epidemiology in disease surveillance and research

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Summary
Participatory epidemiology is the application of participatory methods to epidemiological research and disease surveillance. It is a proven technique which overcomes many of the limitations of conventional epidemiological methods, and has been used to solve a number of animal health surveillance and research problems. The approach was developed in small-scale, community animal health programmes, and then applied to major international disease control efforts. The Global Rinderpest Eradication Program adopted participatory epidemiology as a surveillance tool for controlling rinderpest. This approach was subsequently used in both rural and urban settings in Africa and Asia, for foot and mouth disease, peste des petits ruminants and highly pathogenic avian influenza. Participatory disease surveillance has made an important contribution towards controlling both rare and common diseases. This paper reviews the principal applications of participatory epidemiology and highlights the lessons learned from field applications. In addition, the authors examine future challenges and consider new areas for research.

Keywords
Animal health surveillance – Developing countries – Epidemiology – Highly pathogenic avian influenza – Participatory disease surveillance – Participatory epidemiology – Rinderpest – Surveillance – Traditional knowledge – Veterinary services – Zoonosis.

Introduction

Participatory epidemiology (PE) (30) is based on conventional epidemiological concepts but uses participatory methods (6, 20) to solve epidemiological problems. It is a practical approach to epidemiology that gives stakeholders a greater role in shaping programmes for:

– public health (18)

– animal health

– disease surveillance

– research.

The techniques of participatory rural appraisal (PRA) are used to formulate the programme objectives, gather epidemiological data and intelligence, and analyse information. Participatory epidemiology recognises that local people have very rich and detailed knowledge about the animals they keep and the infectious and zoonotic diseases that can gravely affect their livelihoods and endanger human health. Local farmers and livestock

owners are often able to describe clinical presentations, epidemiological patterns and principal pathological lesions using a vocabulary of specific disease terms in local languages that correspond to Western clinical case definitions. This body of knowledge has been termed 'existing veterinary knowledge' (EVK) (30). Participatory epidemiology learns from local knowledge, leading to disease control programmes that are both acceptable to their stakeholders and effective.

The PE approach was developed to overcome the constraints in applying conventional epidemiology and formal research in developing countries. Conventional epidemiology can be expensive and logistically complex, producing large quantities of information from formal surveys that are often biased, spatially, behaviourally and logistically (6). Further, as researchers generally do not understand the local context, quantitative information is often misinterpreted.

Participatory methods were first used to approach epidemiological questions in small-scale, community-based projects, where technical assistants had close contact with livestock-keepers, and needed practical methods of assessing targeted animal health activities within realistic time frames. As experience with EVK and participatory methods increased, veterinary field epidemiologists realised that there was tremendous potential to develop participatory approaches to epidemiology as surveillance, outbreak investigation, and research tools, in a variety of rural and urban settings.

As PE evolved, an innovative participatory methodology for surveillance programmes was developed in response to the needs of the Global Rinderpest Eradication Program (31). This approach is called 'participatory disease searching' and is a form of active surveillance that taps into traditional information networks to track down and diagnose outbreaks of infectious disease. Later, this approach was applied to a broad range of diseases in Pakistan. It helped to clarify the clinical picture for rinderpest, as well as establishing a database on the animal health priorities of livestock owners at the national level (29). The concept of disease searching was broadened to become 'participatory disease surveillance' (PDS). This approach to surveillance is grounded in the definition of surveillance as 'information for action' (36, 39), and is now recognised in the World Organisation for Animal Health (OIE) guidelines for rinderpest surveillance (45) and as an important approach for general surveillance (44).

Early applications of PE focused on pastoral communities, whose livelihoods were heavily dependent on livestock and who had limited exposure to Western veterinary medicine. Since then, the approach has been extended to a diverse range of communities that includes mixed livestock agriculture systems and even peri-urban and intra-urban livestock production systems. In the case of Pakistan, PE techniques were used to evaluate the size and rinderpest status of the urban buffalo population in Karachi. Most recently, PDS has been applied in Indonesia in rural and urban settings, including Jakarta, one of the most densely populated cities in the world. The purpose of PE and PDS is to enable public health professionals, government officials and local people to work together to appraise, analyse and plan programmes which are appropriate to their particular region.

This paper will provide an overview of PE techniques. Subsequently, the authors describe some practical applications of PE and PDS, together with key lessons from those experiences. Lastly, the authors highlight future challenges and directions.

Overview of participatory epidemiology methods

Participatory approaches are based on open communication and transfer of knowledge, using a toolkit of methods guided by some key concepts and attitudes. The methods include:

– semi-structured interviewing

– focus-group discussions

– ranking and scoring disease observations

– a variety of visualisation (e.g mapping and modelling) and diagramming techniques (e.g. seasonal calendars and historical timelines).

These methods can be combined in a number of different ways, depending on the topic under investigation, and result in a combination of:

– observations from the participants

– semi-quantitative scores

– quantitative data.

In PE, as in PRA, all information should be validated by cross-checking, using multiple techniques and informants: a process called 'triangulation'. In PE, a basic assumption is that investigators cannot fully anticipate the priorities and problems of the communities they study. This assumption helps to avoid many biases associated with conventional epidemiology approaches. Thus, the process empowers the stakeholders, since they are the ones who identify and describe the problems. This tactic ensures that field approaches are flexible and allow time for the 'discovery' of new information. Practitioners of PE have a respect for all forms of knowledge and a genuine interest in learning from

the different points of view of diverse stakeholders. These practitioners are good listeners, who listen with respect but also critically review all information.

Listening to, learning and understanding traditional knowledge is the key to good research and assessments at the community level. A primary objective of PE is to gain an overview of the range of local disease terms and how farmers process and perceive information. For example, the Somalis have a very detailed grasp of disease vectors and have local names for most species important in disease transmission. Like the Somalis, the Karamojong of Uganda are pastoralists, but do not associate insects or arthropods with specific diseases (2). Understanding these factors is essential to carrying out disease investigations and designing control programmes that work.

In many societies, it is difficult to obtain accurate quantitative information through direct questions, such as those used in structured questionnaires, because interviewing may not be a common form of communication. The results of direct questions are often misleading because they pressure people into providing an answer. Such results should be validated by using multiple approaches and informants (19). Examples include questions about herd size, and morbidity and mortality due to specific diseases. Alternatively, livestock owners usually feel quite comfortable talking about specific animals and can give a detailed history of individual animals and their offspring (13). This approach can be used to build up detailed information on a herd, which allows accurate calculation of quantitative indicators.

Sampling methodologies used in PE include the selection of key informants and a risk-based approach to identifying sampling sites (37). Random sampling is sometimes employed when participatory approaches are used to make quantitative estimates. Key informants are individuals or groups who are likely to have well-developed knowledge or an especially relevant perspective of the problem under investigation. In risk-based sampling, the information on the target disease available from key informants and secondary sources is used to create a qualitative risk map. Initial sampling sites are selected from the risk map, and subsequent sampling sites are based on the trail of information revealed by the study. As information is collected, the risk map and overall study hypothesis are refined in a process of iterative analysis.

The core method in the toolkit for PE is the semi-structured interview. This is when interviewers use checklists of topics to be covered rather than a structured questionnaire (Fig. 1). The interviewer introduces a topic using an open-ended question. An example of an open-ended question would be: 'What diseases affect your chickens?' This allows the respondents to provide direction to the interview and describe problems in their own terms.

Fig. 1
Interviews can be conducted with small groups or individual key informants
In this case, a participatory disease surveillance team leader is interviewing a traditional healer, *siana*, in Pakistan. Note the position and body language of the interviewer. Rather than seeking to extract information at source, his posture reflects an attitude of respect and an interest in learning

Once the participants have noted and described problems, the team can then ask probing questions to fill in any gaps and to check for internal consistency within the individual accounts. A number of ranking and scoring techniques exist, including:
- simple ranking
- pair-wise ranking
- piling techniques.

One main group of techniques uses a process called 'proportional piling' (21). In this technique, the participants are given a number of counters (for example, 100 beans) and asked to divide them into piles, representing a number of categories, by agreed criteria. For example, the community may have identified five principal poultry diseases. Respondents could then be asked to divide the pile into five smaller piles, to represent the relative impact of each disease on their livelihood. Proportional piling techniques can be adapted to study issues such as:
- disease prevalence and incidence
- mortality rates
- clinical presentation
- epidemiological risk factors
- disease impact
- the efficacy of disease interventions.

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

Among visualisation techniques, seasonal calendars, mapping and diagramming exercises are the most common. Participatory mapping is one of the most useful tools in the PE toolkit, and is often a good technique to start with, as it involves several people and can stimulate much discussion and enthusiasm. It can be used to gain an overview of:

– the spatial distribution of community resources
– herding patterns
– livestock population contact structure
– the spatial distribution of risk factors.

In PDS, participatory mapping has been used to map disease outbreaks, both spatially and temporally, within rural and urban communities. Respondents indicate the locations and dates of clinical disease events and describe the sequence of events, which reflects how diseases spread through communities and populations. This can highlight key risk factors and important epidemiological information, as well as contributing data to aid in estimating transmission parameters for disease models.

Participatory disease surveillance requires a clinical case definition tailored to the specific disease which will capture all cases of the disease and which is linked to laboratory diagnostic criteria for confirmation. For diseases known to be endemic, this involves detecting events which fit the clinical case definition, followed by an appropriate field-based diagnostic test. For diseases where field diagnostics are not available, or for suspected disease introductions into non-endemic areas, the diagnostic protocol includes appropriate sample collection and confirmation from an accredited diagnostic laboratory. For reportable diseases, these case definitions must be endorsed by the relevant veterinary authority and consistent with OIE guidelines (45).

Examples of applications

Early applications of PE focused on needs assessment when establishing community-based animal health programmes. Here, participatory assessments were used to identify the range of diseases known to farmers and livestock owners and to indicate their disease status in project areas. An important step in this process is to rank diseases in terms of their importance to livestock owner's livelihoods (15, 22, 32). Participatory epidemiology assessments were also used to gain an appreciation of local knowledge, attitudes and practices in order to design community animal-health-worker training programmes that built on EVK. Out of these applications, tools and methods were developed for semi-quantitative or relative estimates of incidence (17, 33). These assessments were also used to understand the way in which communities approached decision-making, so that animal health programmes would reinforce local institutions and have greater local acceptance.

Within the community-based animal health programmes of the Pan African Rinderpest Campaign, it rapidly became apparent that pastoralists had an excellent grasp of the dynamics of rinderpest in local populations and could direct disease surveillance experts to rinderpest foci. This approach made several important contributions to rinderpest eradication. First, it identified the final foci of infection in remote areas for eradication efforts. As this approach fully described the outbreaks and community context, it gave immediate guidance on how best to control the disease. Lastly, PDS became an important tool in confirming the absence of clinical disease in a number of countries as part of the process of certification of rinderpest eradication (24, 44). Participatory disease surveillance programmes were established in Ethiopia, Kenya, Sudan, Uganda and the Somali ecosystem, as well as in Pakistan, within the context of rinderpest programmes co-ordinated by the Food and Agriculture Organization (FAO) and the Interafrican Bureau for Animal Resources of the African Union (AU-IBAR). These early experiences led to the establishment of a few expert teams at the national level who could be dispatched to high-risk areas to carry out targeted disease searches. One of the challenges of these programmes was sampling methodology. There was a tendency on the part of national governments to favour survey methods rather than embrace the investigatory approach that is at the heart of PDS.

As experience with PE increased, this approach was soon being used to solve complex epidemiological questions (35), including unravelling the underlying aetiology of challenging clinical syndromes (4, 5). It was also employed, in combination with quantitative techniques, to develop epidemiological models of disease transmission (25, 26, 27). Table I summarises PDS programmes from around the world, their target diseases, and the number of experts, trainers and master trainers developed by each programme.

In Pakistan, PDS was of prime importance to the Global Rinderpest Eradication Program, supplying information to support an application for OIE accreditation of freedom from the disease. However, PDS went well beyond this.

Table I
Summary of national participatory disease surveillance programmes from 2002 to 2007

Country	Programme dates*	Number of PDS practitioners	Administrative level of coverage	Number of PDS trainers	Number of PDS master trainers	Target disease	Important diseases for farmers identified by PDS
Pakistan (24, 25)	April 2002 – May 2005	50	Province	14	7	RP, FMD and PPR	FMD, PPR, HS and PPH
Afghanistan	June 2005 and February to March 2006	7	Province	0	0	RP, FMD and PPR	FMD, PPR, endo-parasites and HS
Tajikistan	June 2005 and October 2006	7	Province	0	0	RP, FMD and PPR	FMD, BQ, theleriosis and PPR
Uzbekistan	June 2005 and October 2006	7	Province	0	0	RP, FMD and PPR	Haemoparasites, brucellosis, endo-parasites and pasteurellosis
Indonesia (16)	January 2006 – January 2007**	350	District	60	3	HPAI	HPAI, ND
Kenya (11)	November 2002 – June 2006	62	National/ Province/ District	3	0	RP, HPAI	ECF, FMD, RP-like syndrome in Ruga, in the Garissa district
Sudan (7, 8, 14, 20, 38, 40, 41, 42)	November 2001 – April 2007	262	National/NGO	13	0	RP, HPAI	PPR, ECF, FMD, MCF and ND
Ethiopia (9)	November 2002 – March 2004	26	National/NGO	0	0	RP	RP-like syndrome at Dolo Odo. RP was ruled out but, even with follow-up, no confirmatory diagnosis could be made
Uganda (10, 18)	October 2003 – November 2005	31	District	0	0	RP	ECF, CBPP, Helminthosis, *Shialukho shekamafugi* (bloody diarrhoea)
Somalia (23)	November 2002	7	National/NGO	0	0	RP	

* Some programmes were not continuous, but involved one or more training periods during the indicated dates
** This is a continuing programme, with increasing numbers of trained personnel
BQ: black quarter disease
CBPP: contagious bovine pleuropneumonia
ECF: East Coast fever
FMD: foot and mouth disease
HPAI: highly pathogenic avian influenza
HS: haemorrhagic septicaemia
MCF: malignant catarrhal fever
ND: Newcastle disease
NGO: Non-governmental organisation
PDS: participatory disease surveillance
PPH: post-parturient haematuria
PPR: peste des petits ruminants
RP: rinderpest

Information on the importance of a number of other diseases to farmers contributed significantly to formulating animal health policies. These diseases included those which were well known to be major problems or notifiable to the OIE (for example, foot and mouth disease [FMD], peste des petits ruminants [PPR] and haemorrhagic septicaemia [HS]), as well as those which were not generally recognised as priorities (post-parturient haematuria, for example). Over all, farmers in Pakistan ranked HS as the most important disease. This was a surprise to many decision-makers, who believed that FMD had the greater economic impact. Farmers indicated that they could cope with the chronic production losses caused by FMD, but not the catastrophic impact of HS. Thus, PDS showed that farmers took a more holistic view and considered economic impact, risks and coping mechanisms when they prioritised diseases (Fig. 2).

As a result of the Pakistan experience, PDS was used to strengthen disease surveillance in Central Asian countries participating in an FAO regional project to enhance epizootic disease control. Programmes were established in Afghanistan, Tajikistan and Uzbekistan, and regional training workshops were used to introduce PDS to these and the other countries involved (Turkmenistan, Kazakhstan and Kyrgyzstan). Training was provided

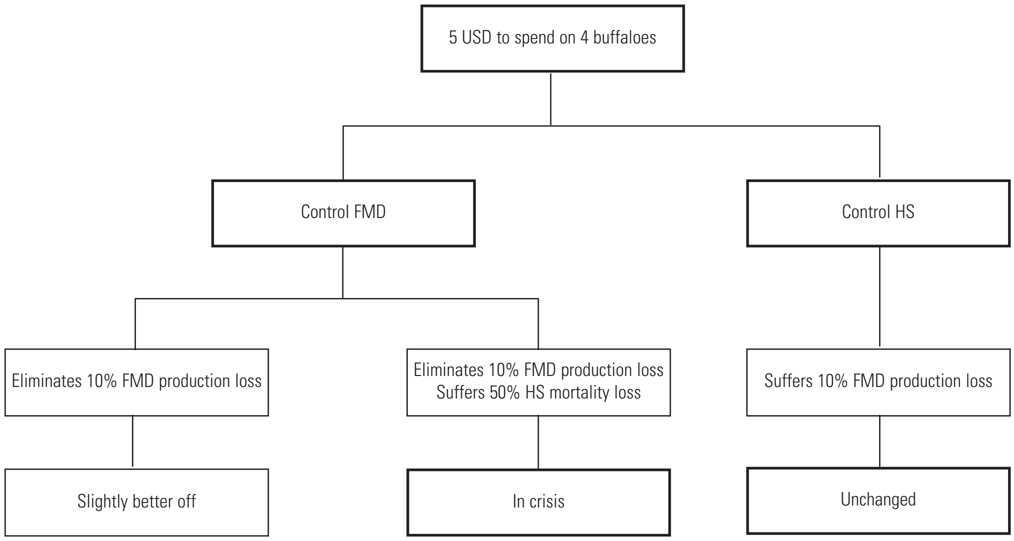


Fig. 2
A decision tree representing the potential outcomes when a Pakistani farmer has five United States dollars USD to invest and must choose between vaccinating four buffaloes against haemorrhagic septicaemia or foot and mouth disease
The example assumes that foot and mouth disease (FMD) would cause a 10% production loss, but an outbreak of haemorrhagic septicaemia (HS) would cause 50% mortality in an unprotected herd. Note that if the farmer chooses FMD control instead of HS control, he or she runs a risk of catastrophic losses in return for only modest gains

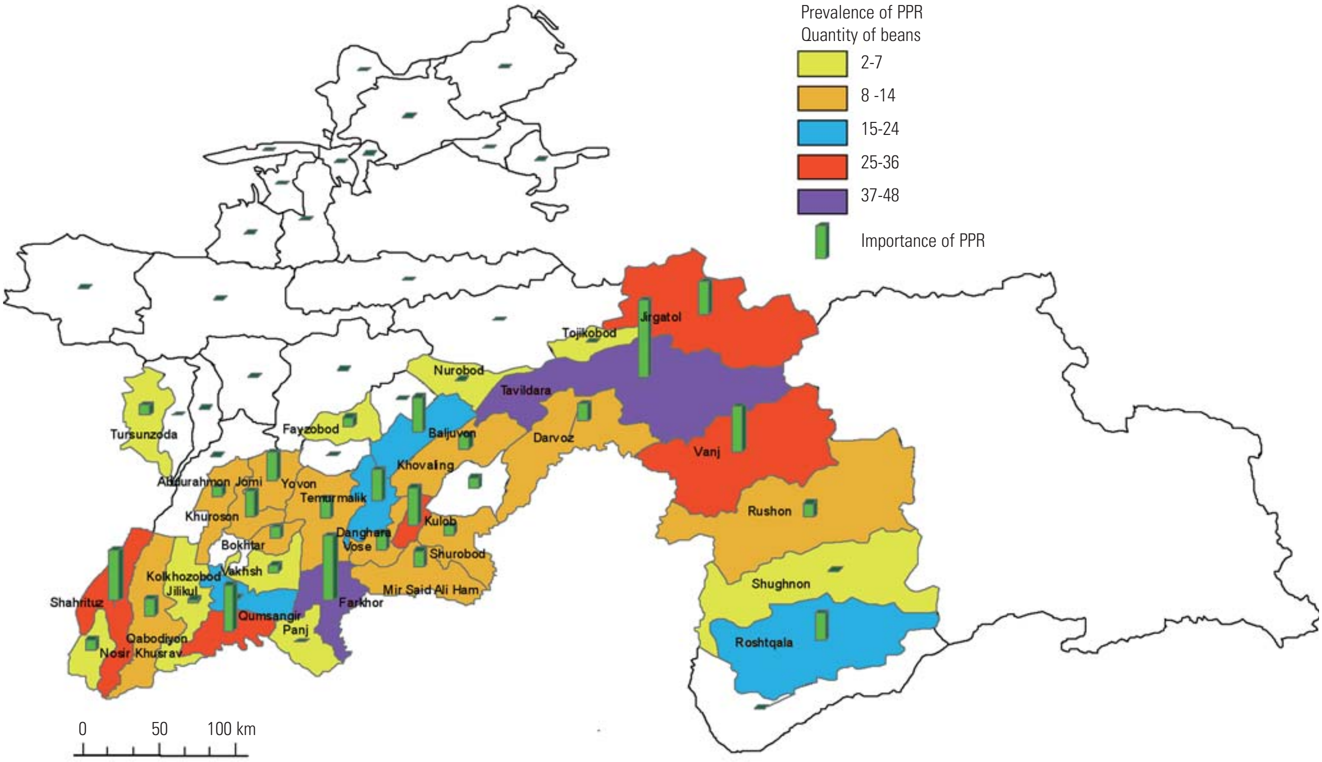
mainly by experts from the Pakistan rinderpest eradication PDS programme.

The Central Asia programme was primarily designed to provide disease information to prove freedom from rinderpest, and did this well by showing clearly that rinderpest was not among the animal health problems that farmers were experiencing. These results were subsequently confirmed by laboratory serological studies. Since 2005, a total of 700 villages have been visited by PDS teams in Afghanistan, Tajikistan and Uzbekistan, with 11,031 farmers participating. Participatory disease surveillance data have shown the importance and relative prevalence of several major diseases, including OIE-notifiable diseases such as PPR and FMD. The results from proportional piling exercises to examine the relative prevalence and importance of PPR to the livelihoods of livestock owners in selected districts of Tajikistan are presented in Figure 3.

As previously, the Central Asia programme was received with scepticism by the veterinarians in the countries involved. However, through training and field experience, veterinarians rapidly became enthusiastic supporters of the approach as they began to recognise the professional stimulation, improvements to the veterinary farmer relationship, and disease intelligence gained. Although modest in terms of investment, the Central Asia programme has proven to be valuable in enhancing national and regional disease intelligence.

To aid in responding to and controlling outbreaks of highly pathogenic avian influenza (HPAI) in Indonesia, the concept of PDS has been extended to include participatory disease response (PDR) teams, trained in social mobilisation techniques (34). The explicit objective of the programme is to implement rapid response tied to early detection through active surveillance – i.e. identifying and quickly containing outbreaks in backyard and small-scale commercial operations (3). As HPAI cases in birds are a potential human health risk, the Indonesian Ministry of Health has also launched a participatory surveillance programme in which medical District Surveillance Officers (DSO) will closely coordinate human participatory surveillance activities with veterinary PDS. The DSOs from the Ministry of Health will actively search for human cases, using risk-based sampling by searching poultry outbreak sites identified by the Ministry of Agriculture teams.

In 2006, the veterinary programme was first implemented in Indonesia as a pilot programme in 12 districts. However, it was rapidly expanded to cover 159 districts, comprising the islands of Java and Bali, as well as two provinces of Sumatra, by May 2007. When the programme was initiated, the extent of HPAI infection was not known. Participatory disease surveillance enhanced the sensitivity of the national surveillance system, and within three months of establishing a joint PDS and response (PDS/R) programme it became clear that HPAI was circulating unimpeded in backyard poultry, with several outbreaks detected per district per month in the pilot areas. Field



Source: Dr Giancarlo Ferrari and Dr Sangimurod Murvatulloev: information derived from the FAO Trust Fund project, 'Controlling animal diseases in Central Asian countries' (GTFS/INT/907/ITA)

Fig. 3

Prevalence and importance of peste des petits ruminants in Tajikistan, as estimated by the participatory disease surveillance programme

Livestock owners were asked to identify all diseases of small ruminants and then divide one hundred counters into piles, representing the relative prevalence of the disease. In a second exercise, they were asked to divide the counters according to the impact the disease has on their livelihoods. The coloured shading indicates the prevalence scores out of 100 that the farmers gave peste des petits ruminants (PPR). This is an indication of how common the disease is, in relation to other diseases of small ruminants. The vertical bar represents the score that PPR received in terms of its negative impact on the livelihoods of the farmers

diagnosis of HPAI in Indonesia is based upon detecting active outbreaks that meet the definition of a 'sudden death outbreak' and which return positive results for the Anigen® type A influenza rapid test. Within the first 12 months of operation, the PDS/R programme detected 800 HPAI disease events (16). The large number of outbreaks detected by the PDS teams overwhelmed the response capacity of the district animal health infrastructure, and led to recognition of the need to re-evaluate the national control strategy. Active HPAI events detected by Indonesian PDS practitioners in January 2007 are shown in Figure 4. A total of 236 HPAI events, confirmed by rapid test, were found in 49 of 121 districts during this one month.

Lessons learned

A key lesson learned from all PE and PDS experiences is that decision-makers can rapidly gain a clear and accurate picture of the disease status of their countries, and the priorities of livestock owners (24). Personnel involved in PDS programmes develop new relationships with and respect for farmers and their knowledge. Participatory epidemiology has achieved significant institutional change, leading to revitalised animal health services, which are now more customer oriented, in Pakistan and other countries (16, 28).

As the PE approach was extended from focused, non-governmental activities to mainstream, public-sector surveillance and response programmes, a number of challenges were encountered. Decision-makers, who were not at first trained in participatory approaches, tended to see PE and PDS as 'just another' survey methodology. This led to the development of the first training workshops for decision-makers, to help these managers use PE and PDS information directly and appropriately.

To develop capacity for PDS an iterative training process has been used to build on and refine concepts using a guided experiential learning process. Staff are first trained in field applications of PE and then given field assignments

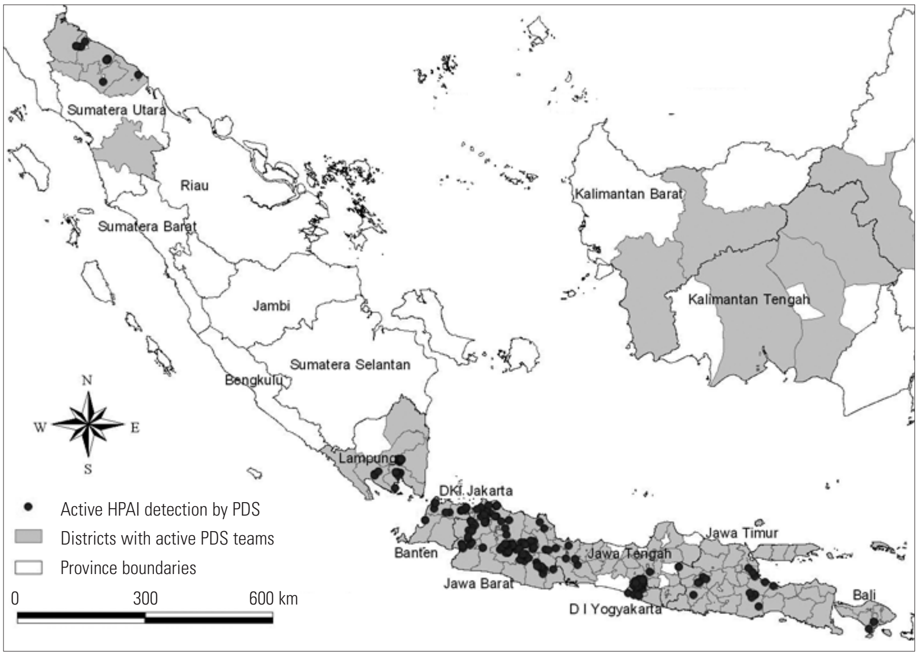


Fig. 4
Detection of highly pathogenic avian influenza by participatory disease surveillance practitioners in Indonesia in January 2007
Districts with active participatory disease surveillance (PDS) programmes in January 2007 are shaded. The circles represent the 236 adequately geo-referenced highly pathogenic avian influenza (HPAI) events that met with the definition of a 'sudden death outbreak' and tested positive by the Anigen® type A influenza rapid test. These events were detected in 49 of 121 districts where interviews were conducted during the month

to develop experience. After completion of their field assignments, promising PE practitioners are invited to become trainers, and guided through the process of conducting their first training courses. In Pakistan, it was found to be beneficial to extend this process further and develop a category of 'master trainers'. These were people who excelled in the application, teaching and supervision of PE techniques, and had several years of experience. Subsequently, master trainers from the Pakistan programme made key contributions to the Central Asia and Indonesia programmes. A new generation of master trainers is now being developed in Indonesia.

As programmes expanded from involving a few expert teams to developing dozens and, more recently, hundreds of teams, methods of data recording needed to be developed that preserved the participatory nature of the programme but allowed for analysis at the national level. One of the key strengths of PE is the open-ended approach, which allows livestock owners to express information within the context of their own knowledge systems. When this information is coded into a database using a structured list of options, much of the value of the information is lost. On the other hand, key information, such as outbreak co-ordinates and test results, need to be recorded in a coherent, easily analysed system. With PDS, the best solution to date has been a simple record form created for the Pakistani programme, which covers one side of a single page. In Indonesia, a much larger recording format was created to try to capture more information in the database and facilitate national analysis. However, the task of data entry proved overwhelming as the number of records reached into the tens of thousands. Elaborate record forms also tend to lead to the degeneration of PE into ordinary questionnaire surveys.

The starting point in building a PE programme is to establish the objectives, framework and resources required for the programme. This requires assessing the national context and gaining agreement from decision-makers on what is expected from the programme, which leads to the preparation of a work plan and budget. Thus, the first step is for a PE expert to carry out a rapid assessment of existing veterinary knowledge, the disease situation and existing national surveillance and research capacity. This information is the basis for designing the overall programme, and also enables the training programme to be adapted to the local context. It is important to bear in mind that, in decentralised government systems, decision-makers must be involved at the national and regional/local levels of government.

The use of participatory methods requires considerable problem-solving skills and the ability to be adaptable. It is not just knowledge; it is learned behaviour. For this reason, experiential learning approaches, based on participation and supervised field practice, are crucial and learning from colleagues is part of the process.

The quality of a PDS programme depends directly on the skills of the personnel. Training programmes should be in local languages. The training of practitioners should be focused on active learning and personal discovery, and involves in-depth field practice and refresher training. National PDS programmes should include annual continuing education for PDS practitioners. When developing trainers, a practitioner should have a minimum of one year of field experience before entering into a 'training-of-trainers' programme. Not all practitioners will be suitable to become trainers, and only a select few may become master trainers.

As Veterinary Services become more and more decentralised, attention needs to be paid to governance at all levels, from national and state level to district and village level. The level of government from which PDS practitioners are drawn depends on the structure of national Veterinary Services and the epidemiology of targeted diseases. Local government should be involved, to ensure that local needs and concerns do not suffer as national objectives are being met. Where appropriate, both public and private veterinary practitioners should be part of the PDS network.

Participatory disease surveillance is a form of active surveillance that should be integrated into national surveillance systems. Data generated by PDS should be maintained as part of a single national database that is consistent with OIE standards and allows transparent and timely reporting of important diseases. All surveillance systems should include objective monitoring and evaluation (including real-time analysis of data quality) to detect anomalies in the system (24). Including this element of accountability in the system will allow national Veterinary Services to find problems early, as well as assure international partners of the reliability of national surveillance reports.

In addition, PDS is highly sensitive, allowing the detection of hard-to-find disease foci. This level of sensitivity must be linked to a laboratory case definition which increases the specificity of the overall case-finding methodology. The clinical case definition is syndromic and identifies a subset of diseases thus casting a broad net to capture suspect events for further investigation. It is the function of field-based rapid tests and laboratory confirmation to provide the specificity. The early detection of disease problems must also be linked to rapid disease-response protocols, based on a realistic understanding of national human and financial resources, including:

– culling
– control of animal movements
– biosecurity
– vaccination
– information sharing.

Many Veterinary Services assume that farmers should come to their offices to report diseases, thus saving costs to the public sector. However, in developing countries, farmers often have to travel long distances to reach veterinary posts and incur significant costs when reporting disease problems. With the privatisation of most curative services, the incentives for visiting veterinary posts have declined. As a result, passive surveillance programmes can be insensitive. Even in cases where veterinary offices are near, there is little incentive to visit and passive surveillance alone does not work. The result is under-estimates of disease prevalence, poor prioritisation when deciding policy and, sometimes, complete failure to detect the presence of an important disease. Wholly passive surveillance programmes are examples of animal-health-market failure, and point to the need for integrated programmes that include active, passive and laboratory-based methods.

National Veterinary Services recognise the value of good surveillance data and the need to reach out to farmers to obtain relevant data through active surveillance. However, this requires choices on funding priorities and a move away from static infrastructure and costly vehicles to dynamic, field-based networks of personnel who interact with farmers in their own environment. In the PDS programmes in Pakistan, two to three teams covered each province and relied primarily on public transport. These limited teams generated more surveillance data than the rest of the Veterinary Service. Participatory disease surveillance is a proven and flexible approach to active disease surveillance that has been adapted to a wide variety of settings.

The future

The Network for Participatory Epidemiology and Public Health has been established to advance the science of PE through targeted research, capacity building, policy enhancement and practitioner education. Co-ordinated by the International Livestock Research Institute (ILRI), the Network includes the FAO, OIE, AU-IBAR, and non-governmental organisations experienced in PE methods.

Regional PDS programmes, such as those in East Africa and Central Asia, were the first to bring countries together to develop a harmonised PDS approach to active surveillance. The Network will build on this approach by strengthening existing programmes and establishing new regional programmes to increase regional co-operation in

surveillance and disease control. Regionalisation will be advanced by testing field programmes to ensure that regional needs are met, thus leading to effective active surveillance programmes that are harmonised within OIE guidelines. Ultimately, this will lead to co-operative approaches for rapid disease response and better targeting of animal health policies, resulting in improved services to farmers and increased access to international markets.

With the increasing international focus on emerging and re-emerging zoonoses, the need for better integration of veterinary and public health surveillance programmes is clear. In Indonesia, veterinary PDS is being used to target participatory public health surveillance for HPAI to the most at-risk human populations – those whose poultry are experiencing outbreaks of active disease. The field of participatory public health can be expanded through active research to identify public health surveillance and response gaps that can be filled using participatory methods (18). Advocacy for policies that recognise Veterinary Services as integral to public health is needed. Innovative ways to integrate PDS workers and participatory public health practitioners in the field are also required, as well as effective models for integrating public health and veterinary surveillance, including the development of unified 'public health' databases.

Partners in the Network are conducting research to expand the application of PE. Promising new fields include:

– emerging and re-emerging infectious disease research

– participatory risk analysis (12)

– participatory impact assessment (1)

– participatory ecosystem health analysis

– participatory value chain approaches.

Incorporating participatory approaches to epidemiology into university curricula will have a long-term impact on the veterinary profession. Debate, discussion and consultation continue to further the process of integrating participatory methods with conventional epidemiological approaches and key international guidelines, such as the OIE *Terrestrial Animal Health Code* (45) and World Health Organization *International Health Regulations* (43).

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L'épidémiologie participative appliquée à la surveillance et à la recherche sur les maladies

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Résumé

L'épidémiologie participative consiste à appliquer les méthodes participatives à la recherche épidémiologique et à la surveillance des maladies. Il s'agit d'une technique éprouvée qui a surmonté la plupart des contraintes des méthodes épidémiologiques traditionnelles et permis de résoudre un grand nombre de problèmes dans les domaines de la surveillance et de la recherche en santé animale. Mise au point dans le cadre de petits programmes communautaires de santé animale, cette méthode a été appliquée ensuite dans des initiatives

internationales de grande envergure pour la prophylaxie des maladies animales. Le Programme mondial d'éradication de la peste bovine a fait appel à l'épidémiologie participative en tant qu'outil de surveillance pour la peste bovine. Par la suite, cette méthode a été utilisée en Afrique et en Asie dans des configurations tant rurales qu'urbaines de lutte contre la fièvre aphteuse, la peste des petits ruminants et l'influenza aviaire hautement pathogène. La surveillance participative contribue de manière significative à la prophylaxie des pathologies rares comme des affections courantes. Les auteurs examinent les principales applications de l'épidémiologie participative en soulignant les leçons tirées de l'expérience sur le terrain. En outre, ils exposent les défis futurs ainsi que les aires nouvelles qui s'ouvrent à la recherche.

Mots-clés
Épidémiologie – Épidémiologie participative – Influenza aviaire hautement pathogène – Peste bovine – Service vétérinaire – Surveillance – Surveillance participative des maladies – Surveillance zoosanitaire – Zoonose.

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Epidemiología participativa en la vigilancia de enfermedades y la investigación

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Resumen
La epidemiología participativa es la aplicación de métodos participativos a la investigación epidemiológica y la vigilancia de enfermedades. Se trata de una técnica contrastada, que permite trascender muchas de las limitaciones de que adolecen los métodos epidemiológicos convencionales y que ha sido utilizada para resolver numerosos problemas de investigación y de vigilancia zoosanitaria. La metodología fue definida ante todo con programas a pequeña escala de sanidad animal comunitaria, y aplicada posteriormente a grandes iniciativas internacionales de control de enfermedades. Al poner en práctica el Sistema mundial de erradicación de la peste bovina se adoptó la epidemiología participativa como instrumento de vigilancia y lucha contra la enfermedad. Más tarde se utilizó el mismo método en zonas tanto rurales como urbanas de África y Asia para combatir la fiebre aftosa, la peste de pequeños rumiantes y la influenza aviar altamente patógena. La vigilancia sanitaria participativa ha contribuido sustancialmente a la lucha contra ciertas enfermedades, algunas raras y otras comunes. Los autores pasan revista a las principales aplicaciones de esta técnica y destacan las enseñanzas extraídas de su aplicación sobre el terreno. Además, examinan las dificultades que se perfilan en el horizonte y consideran nuevas líneas de investigación.

Palabras clave
Epidemiología – Epidemiología participativa – Influenza aviar altamente patógena – Peste bovina – Servicios veterinarios – Vigilancia – Vigilancia sanitaria participativa – Vigilancia zoosanitaria – Zoonosis.

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