The value of community participation in disease surveillance: a case study from Niger*

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SUMMARY

A team of researchers, including one behavioral scientist (S.M.N.) and three epidemiologists (L.Q., O.S. and S.N.) conducted community analyses to assess the social and cultural factors that affect the detection and reporting of disease cases in a surveillance system, using acute flaccid paralysis (AFP) surveillance in Niger as a case study. Over a 60-day period in the country, the research team reviewed written field reports and interviewed epidemiologists, nurses, community members and persons in governmental and non-governmental organizations. Overall, we found that the logistical difficulties of travel and communication, which are common in developing countries, constrain the conventional surveillance system that relies on epidemiologists visiting sites to discover and investigate cases, particularly in rural areas. Other challenges include: community members' lack of knowledge about the possible link between a case of paralysis and a dangerous, communicable disease: lack of access to health care, including the low number of clinics

and health care workers; cultural beliefs that favor seeking a local healer before consulting a nurse or physician; and health workers' lack of training in AFP surveillance. The quality of surveillance in developing countries can improve if a community-based approach is adopted. Such a system has been used successfully in Niger during smallpox-eradication and guinea worm-control campaigns. In a communitybased system, community members receive basic education or more extensive training to motivate and enable them to notify health care staff about possible cases of disease in a timely fashion. Local organizations, local projects and local leaders must be included to ensure the success of such a program. In Niger we found sufficient quantities of this type of social capital, along with enough local experience of past health campaigns, to suggest that a community-based approach can improve the level of comprehensiveness and sensitivity of surveillance.

Key words: Africa; community-based surveillance; polio eradication; social assessments

INTRODUCTION

There is a growing awareness among health professionals that community participation contributes to the success of health promotion programs (Wallerstein and Bernstein, 1988;

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Thomas, 1990; Freundenberg and Trinidad, 1992). It is also an important means of changing people's actions and attitudes towards the causes of ill health (Rifkin *et al.*, 1988), and is key to achieving the goal of good health for all (Tsouros, 1990). It is also recognized that community participation is an effective means of achieving cost-effective and sustainable health objectives, as opposed to 'top down' and heavily

bureaucratized systems of health care delivery. In Nigeria, for example, the development and adoption of systems for the distribution of Ivermectin to fight onchocerciasis in which communities were active was preferred over the more expensive distribution system through governmental and non-governmental programs that led to low coverage (Onwuyekwe *et al.*, 1999).

Community participation in health projects, especially in developing countries where populations are the poorest and most powerless, was strongly advocated at the Alma Ata Conference in 1978, in which 138 countries adopted the declaration that 'people have the right and the duty to participate individually and collectively in the planning and implementation of their health care' [World Health Organization (WHO)/ UNICEF, 1978; Asthana and Oostvogels, 1996]. Community members participate in health projects with neighborhood organizations, selfhelp groups and other voluntary organizations (WHO, 1992). Effective community participation in health does not simply involve community members working side-by-side with health care professionals and doing what they are told to do; it involves professionals and their clients sharing both power and responsibility.

In this report, the research team discusses the social and cultural factors that affect the comprehensiveness of a surveillance system in the developing world, using acute flaccid paralysis (AFP) surveillance in Niger as a case study.

Surveillance of AFP and polio eradication

Poliomyelitis is a highly infectious viral disease that can lead to extensive paralysis or death. There is no known cure. Between 70 and 90% of infected persons are children under the age of 3 years. Due to ongoing polio eradication efforts, the number of poliomyelitis cases has decreased worldwide, from an estimated 350 000 in 1988 to 20 000 in 1999 (Aylward *et al.*, 2000). Polio remains endemic in parts of Africa, the Indian subcontinent and the Eastern Mediterranean region.

To halt the transmission of polio in an area, the WHO recommends a three-part vaccination strategy: (i) routine vaccination of infants less than 1 year old with at least three doses of oral polio virus vaccine (OPV); (ii) the administration of supplemental doses of OPV to all children under the age of 5 years during National Immunization Days to decrease the widespread circulation of the polio virus rapidly; and (iii) localized

'mopping up' vaccination campaigns to eliminate the last remaining chains of transmission of the polio virus [Centers for Disease Control and Prevention (CDC), 1999a; WHO, 1999; Sutter et al., 2000]. For countries to be certified by WHO as polio-free, they must demonstrate that they have an AFP surveillance system that is sensitive enough to detect any remaining cases of AFP (by obtaining a rate of 1 per 100 000 children <15 years old). The detection and reporting of AFP cases are the critical steps in the process of AFP surveillance (see Figure 1). When countries achieve (i) an annual AFP reporting rate of at least 1 case per 100 000 people <15 years of age and (ii) targets for the timeliness and proportion of specimens collected and tested, they demonstrate that their surveillance systems are adequate to detect wild polio virus circulation due to indigenous transmission or virus importation and that they have indeed eradicated polio.

Although the reporting rate for AFP cases has improved substantially in Africa, from 0.8 per 100 000 in 1999 to 1.3 per 100 000 in 2000, and the proportion of persons with AFP from whom adequate stool samples were collected increased from 31 to 52% in the same years (CDC, 2001), wild polio transmission is still reported in countries like Nigeria, the Democratic Republic of Congo, Angola and Ethiopia.

AFP surveillance in Niger

AFP surveillance activities in Niger are conducted by the Direction du Systeme National d'Information Sanitaire (DSNIS), which is also responsible for the surveillance of other diseases, such as measles, meningitis, vellow fever and cholera. The national surveillance system employs 49 epidemiologists, one in each of the eight regions and 41 districts of the country. Efforts to strengthen AFP surveillance in Niger began in 1997 and grew in the following years with increased efforts to train epidemiologists and nurses, and to provide logistical support for transportation and communication. As a result of these efforts, supported by the US CDC, the WHO and its partners, the number of reported AFP cases increased from 12 in 1997 and 1998 to 110 in 1999 (CDC, 1999b), of which nine were confirmed polio cases. Niger's non-polio AFP rate improved from 0.10 per 100 000 in 1998 to 1.1 per 100 000 in December 2000. Table 1 summarizes performance indicators for Niger's AFP surveillance system as of December 2000.

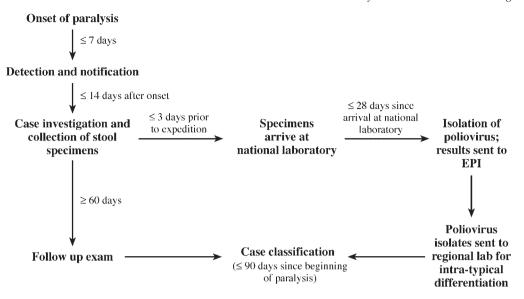


Fig. 1: AFP surveillance procedures.

Table 1: AFP surveillance performance indicators in Niger as of December 2000

	Current	Objectives
Non-polio AFP rate Cases with two stools <14 days ^a Stools specimen arriving at DSNIS 3 days after collection Investigated cases ^b	1.1 43% 73.3% 62	1.00 80% 80%

^aCases for which, as recommended, two stools were collected in <14 days after onset of paralysis.

Source: (WHO, 2000).

Country characteristics and potential barriers to disease surveillance

Niger is a west African country, 1 267 000 km² (490 000 square miles) in size (slightly less than twice the size of Texas), with a population estimated at 11 million in 2000. Two-thirds of this vast, landlocked country is desert. Economically, Niger is ranked by the World Bank as one of the poorest countries in the world. In 2000, the average annual income per capita was \$190, and life expectancy was 41 years for both men and women. Niger is divided into eight major administrative regions, called *departements*, and 41 districts.

Health care in Niger may be provided by local traditional healers and from a system of Western medicine, including 429 health centers, eight major hospitals, and a few private clinics in urban areas. In Niger, the population a health center serves corresponds to the number of people living within 15 km (~8 miles). On average, only

30% of Nigerian people have access to health care provided by a system of Western medicine (DSNIS, 2000), but in many rural areas the proportion is as low as 15%. Access to health care is reduced by three major factors: (i) the limited number of health centers; (ii) long travel distances to and from health care facilities; and (iii) high population mobility, especially in the northern part of the country, which is inhabited by nomadic populations. The country has significant limitations with respect to transportation and communication, and many rural and nomadic people who live within the 15-km range, especially in the north and northeastern parts, have no transportation and rely on walking.

In traditional AFP surveillance, epidemiologists periodically visit pediatric wards of hospitals in major cities to review patients' records and search for AFP cases to investigate for the presence of the polio virus. For such a model to be functional, there must be adequate transportation, communications,

bAs of August 2000.

trained and committed staff, and record keeping. Below, we discuss the importance of these factors and their constraints in Niger.

Transportation

Transportation must be available to ensure that staff are mobile and can make timely visits and investigations (to collect stool specimens for example). Poor road conditions add to the difficulties of transportation. In 1996, Niger had only ~798 km (453 miles) of paved roads and 9303 km (5286 miles) of unpaved roads (The World Fact Book, 2001). In a few districts, some epidemiologists received motorcycles provided by WHO. Other international donor agencies that are involved in health care, such as UNICEF and Helen Keller International, have also provided motorcycles to nurses in some districts. However, the majority of nurses and epidemiologists have no means of transportation and hence cannot travel to the remote and desert areas of the north and north-east. Less than one-third of the epidemiologists and nurses in rural areas who are involved in the detection and reporting of AFP cases have means of transportation.

Communication

Ideally, a good communication network allows for the regular flow of information between hospital staff members and epidemiologists in traditional disease surveillance. However, in 1995, only 13 000 main telephone lines in Niger served the main cities, which are concentrated in the southwest (Central Intelligence Agency, 2001). Radiotelephone communications and microwave radio relays are needed to communicate with rural areas. Less than one-third of the health centers in these areas have these means of communication, provided, in part, by WHO, and most rely on occasional visits by people with cars to send messages to the nearest towns.

Trained and committed staff

It is important to have a corps of trained physicians and nurses who are able to diagnose and investigate AFP cases, and who are committed to recording and reporting all suspected cases. Although previous WHO teams have attempted to train health care staff in AFP surveillance procedures in Niger, the number of trained health staff may be insufficient as a result of the high rates of staff turnover, especially among women who frequently move with their family, looking for work opportunities. The consequence of the

lack of trained staff is that cases of AFP may be undiagnosed.

Record keeping

A good record-keeping system by physicians and nurses enables epidemiologists to identify suspected cases of AFP through record reviews. Most health centers in Niger, whether in cities or rural areas, do not have a systematic and/or automated way of keeping and tracking patient record entries, including diagnoses and services provided. The widespread use of loose papers increases the risk that records will be lost, and handwritten notes are often illegible.

Objectives

This article presents findings from a WHO consultancy mission in Niger from January to April 2000, in which the authors conducted community analyses to assess the social and cultural factors that affect the detection and reporting of AFP cases in Niger's rural areas. Our investigation proceeded based upon the premise that in poor and underserved areas, community participation can improve health. In particular, we believed that community participation could improve AFP case finding and the initial notification of appropriate health care professionals. All currently accepted descriptions of effective community participation share one important feature—a level of commitment and involvement by community members that transcends mere participation and includes decision making for a project's goals and implementation plans (Paul, 1988; Bracht and Gleason, 1990; Eng and Parker, 1994). We discuss the social and cultural bases for community participation to improve AFP case finding and the initial notification of appropriate health care professionals.

METHODS

The research team used mixed methods of data collection to learn as much as possible about the constraints on AFP surveillance in Niger and about opportunities to enhance surveillance.

First, the team consulted printed resources to familiarize ourselves with previous WHO missions in polio eradication, and details of AFP surveillance in Niger and worldwide. We also met with officials of governmental and non-governmental organizations (NGOs) in Niger who participate

in polio eradication, including CARE (Care International UK), CARITAS (Caritas Internationalis), Helen Keller International, the US Peace Corps and UNICEF. During these meetings, we learned the roles of these partners and their experiences of AFP surveillance issues in Niger.

The team visited all of Niger's eight administrative regions and 38 of its 41 districts. The community analyses consisted of both unstructured and structured interviews, and observation of interactions in and around the health centers. Unstructured interviews, using in-depth and open-ended questions, were conducted with epidemiologists, health care workers and community members (including public administrators, local traditional healers and clients visiting the health centers). The structured interviews were conducted with a convenience sample of 102 infirmier major (head nurses) out of the 370 nurses whom we met in 80 rural health centers. Our aim was to uncover each informant's views on constraints on AFP surveillance and opportunities for community participation.

In addition, the research team reviewed reports from 33 AFP cases investigated in 1999, including sources of detection/reporting and dates of onset of paralysis. The purpose of this review was to determine the extent to which community involvement contributes to case detection and reporting.

RESULTS

The results of the structured interviews with nurses are summarized in Table 2. They include the following issues identifying limitations to an effective surveillance system in Niger.

Lack of community awareness. The nurses unanimously reported that many rural community members are not educated about what they should do and why when their children are

Table 2: Barriers to AFP surveillance in Niger according to 102 nurses in 62 rural health centers

Barriers	Responses (%)		
Lack of community awareness	100		
Lack of access to health	87		
(or distance from health centers)			
Cultural beliefs	75		
Shortage of health staff	75		
Lack of trained or qualified health staff	62		

suddenly paralyzed. They explained that to encourage parents to bring their children to hospitals or health centers where AFP cases could be identified, it is important to give parents vital information, such as the fact that paralysis may be caused by the polio virus that can spread and infect others in the community, and that parents need to take their paralyzed children to the nearest health center as early as possible. The nurses also commented that timely reporting should be emphasized.

Lack of access to health care. Eighty-seven percent of the nurses who were interviewed said that lack of access to health care for the majority of people is a barrier to routine immunizations and AFP surveillance. Under these circumstances, there are fewer opportunities for interfaces between health care staff and children who are at risk for polio. Lack of access constrains the detection and reporting of AFP cases by limiting opportunities for cases to be observed and investigated.

Cultural beliefs. Seventy-five percent of the nurses reported that cultural beliefs are a major constraint on AFP surveillance. Our conversations with opinion leaders supported the significance of this factor. According to nurses and opinion leaders, many parents believe that paralysis is caused by some spiritual or divine intervention. As a result, they consult with traditional healers before they visit health centers. Our interviews with women whom we met in waiting rooms in health centers confirmed the importance of cultural beliefs. The period from when parents start seeing a local healer to when they realize that there is no improvement and therefore decide to go to the health center is 2-4 weeks, and hence the detection, reporting and investigation of AFP cases are either prevented or delayed.

Shortage of health care staff. Seventy-five percent of the nurses perceived that staff shortages are barriers to the detection and reporting of AFP cases. Many of the head nurses we interviewed complained of being short-staffed. One-third of the 80 health centers that we visited have only one nurse who sees an average of 40–60 patients each day. Because nurses in these centers are overloaded, they tend to spend less time with patients and often take care of only the most urgent and critical cases involving diseases such as meningitis, diarrhea and malaria. Under these

circumstances, cases of paralysis may be overlooked and/or unrecorded. In many instances, nurses do not examine children who display AFP symptoms; rather, they refer them to orthopedic wards of large city hospitals for rehabilitation with no follow-up.

Lack of trained, committed staff. Sixty-two percent of nurses found lack of trained staff to be a problem. The consequences of this were evident in the results of our unstructured interviews. We found that many nurses assume that young children cannot stand up, walk or otherwise move their limbs because they suffer from malnutrition. Thus, they dismiss the potential polio virus infection and tell parents to feed their children more without examining the children or diagnosing them further. In 13 (16%) of the 80 rural centers that we visited, staff reported that there were no staff members who had received training on AFP surveillance, although training courses had been held previously.

Review of AFP case reports and significance of community-based surveillance

Table 3 shows the distribution of 33 AFP cases by sources of detection and reporting in 1999, and underscores the potential contribution of community involvement in AFP surveillance.

Of the 33 cases, 18 (54%) were detected and reported by community agents and parents, as a result of awareness campaigns sponsored by community agents. These 18 cases are thus referred to as community-based surveillance (CBS) cases. Within the CBS cases, one-third were reported by community agents and two-thirds were reported by parents.

The remaining cases make up the non-CBS category, i.e. those that were detected and reported fortuitously, without the conscious decision of the parents to contact a nurse or epidemiologist with the purpose of reporting

a suspected AFP polio case. Among non-CBS cases, two-thirds were discovered during visits or consultations, and one-third were discovered during National Immunization Days, held between October and December 1999. Although there is no statistical difference between the two main categories (CBS versus non-CBS categories). the high proportion of cases declared by parents and community agents indicates that community members contribute significantly to the detection and reporting of cases. An equally important consideration is that these cases were reported within the time frame (3-20 days; the recommended period is 14 days), when there is a higher chance of the polio virus being isolated. We believe that the development and expansion of CBS to include more communities would increase the detection and reporting of cases, especially in the absence of regular National Immunization Days and in areas with few health care services.

DISCUSSION

In light of the constraints identified in Niger, using AFP surveillance as an example, it is important to implement an approach to detecting and reporting cases of disease that is locally relevant, in particular one in which community members themselves can participate and make significant contributions to. This is a CBS approach or a participatory surveillance system in which community members are trained and have their awareness raised to enable and motivate them to report cases in a timely fashion to health care staff in their areas. Potential contributing factors, such as local and indigenous organizations and cultures, are used to support or facilitate the process. In support of the CBS approach are findings from these community analyses, in which we identified several factors likely to facilitate effective community participation in detecting and reporting AFP cases in rural Niger. These factors include

Table 3: Number of AFP cases notified by source [CBS and non-CBS (n = 33)]

Sources	CBS	(% S)	(% T)	Non-CBS	(% S)	(% T)	Total
Community health agents	6	33%	18%	_	_	_	6
Parents	12	67%	36%	_	_	_	12
Consultations	_	_	_	10	67%	30%	10
NIDs	_	_	_	5	33%	15%	5
Total	18	-	-	15	_	-	33

[%] S, percent within source. % T, percent of total cases.

local project/programs, community social capital, and experiences in past disease-eradication programs, including smallpox and guinea worm.

Local projects/programs

Many development projects and programs that are funded by international and national NGOs operate in rural communities of Niger. Organizations that sponsor these projects/programs include European Economic Community (EEC) member countries, specialized organizations of the United Nations such as UNICEF, and international private organizations like CARE. These organizations sponsor community projects related to the environment, agriculture, livestock production and marketing, credit schemes for women, family planning and nutrition, and social rehabilitation of the physically handicapped. During field visits, our team identified at least six projects in each rural community. For the most part, these community-based projects aim to develop community capacity. In the process, they recruit and train local staff and conduct activities that include education (raising awareness) and, in some cases, data collection. The projects implement these activities by conducting home visits, holding town meetings, or maintaining regular contact between their staff and community members. AFP surveillance can benefit significantly from the presence and activities of these projects. Most projects in the rural areas we visited employ a number of people including enumerators, midwives, community health agents and secouristes (nurse's aides who are trained to provide first aid in remote rural areas). AFP surveillance project staff could partner these individuals, as well as members of indigenous associations, to raise awareness among the population and to provide feedback to nurses in health centers and epidemiologists about suspected cases encountered during home visits or public meetings. This type of partnership is feasible and would significantly help to improve access and to solve the lack-of-awareness problem. In addition, messages to debunk cultural myths about the causes and cures of polio can be effectively developed and disseminated using local project/program staff as agents.

Social capital

The term social capital refers to features of social organization, including processes and conditions

among people, that increase mutual trust and facilitate coordination and cooperation which lead to the achievement of community goals (Putnam, 1995; Ichiro et al., 1997). A recent report by the Institute of Medicine defined social capital as characteristics of communities stemming from the structure of social relationships that facilitate the achievement of individuals' shared goals, including the quality of social networks and the by-products of these networks (Institute of Medicine, 2000).

The presence of many indigenous grassroots organizations in rural communities of Niger is a strong indicator of the level of development of their social capital. Local community organizations in rural Niger are diverse (youth clubs, parent-teacher associations and women's associations, for example), and the local issues that they address include village education/literacy, economic development and health. These organizations can contribute to the capacity of communities to participate in AFP surveillance by using their mobilizing power to reach out to large numbers of people and motivate them to be proactive in identifying and reporting suspected AFP cases to local clinics or health centers.

Other elements of social capital in Niger's rural communities include local opinion leaders, such as village chiefs, healers and community health agents, who enjoy loyalty among community members. The status and roles of these individuals make them desirable partners in AFP surveillance, especially for community outreach activities. Traditional healers, for example, are generally consulted for cases of paralysis and are therefore in a position to be aware of potential AFP cases at an early stage. If included in the AFP surveillance process, these healers can effectively direct their followers or clients to local clinics or district epidemiologists for investigation. Village chiefs are members of village health committees (COSAN) and village health affairs management teams (COGES)—two distinct decision-making bodies found in most communities throughout Niger with elected and widely supported officials -who can foster the dissemination of health information and influence health practices among villagers. Their input in AFP surveillance could include encouraging heads of households to assume the responsibilities for reporting suspected cases to their local health centers.

About two-thirds of the head nurses of health centers that we visited said that they collaborate with agents communautaires (community agents, i.e. field staff employed by projects/programs) in some of the villages that they serve. Such agents are recruited especially among secouristes, midwives, femmes relais and animatrices. Femmes relais are women who serve as intermediaries between health center staff and other women who live in the community. Animatrices are a specially trained corps of women who conduct training activities that are mainly for family development and are oriented towards women. The training activities cover many areas including sewing, health prevention practices and child rearing, for example. Currently, the roles of agents communautaires are limited to the dissemination and collection of information on nutrition and reproductive health. Over the years, many of these agents have developed close relationships with their constituents. Since the nature of their work gives them access to homes and many opportunities to discover and report potential AFP cases, it would be beneficial to include AFP surveillance among their activities.

Past experiences

Two major disease-eradication campaigns, smallpox in the 1970s and guinea worm in the 1980s, preceded the current campaign to eradicate polio in Niger. We found that many of the agents who participated, particularly in the guinea wormeradication campaign, are still living in their areas of service, are able to work, and are experienced in disseminating health information, motivational speaking and conducting surveillance. Thus, they represent untapped resources and could make a significant contribution to AFP surveillance if recruited and trained.

CONCLUSIONS AND RECOMMENDATIONS

It is important to intensify AFP surveillance efforts in Africa in general, in order to sustain current achievements and make progress, especially in ensuring that reports are received from rural areas. Even though Niger achieved the target reporting rate at the end of the year 2000, it is critical to ensure and maintain a strong and appropriately sensitive surveillance system, especially in border areas and endemic countries like Nigeria. Logistical realities in rural areas leave open the possibility that undetected transmission could exist.

The conventional surveillance system that relies on epidemiologists to visit sites to find and investigate cases may be significantly constrained in rural Niger, particularly due to logistical difficulties in travel and communication. There is evidence that these factors have limited the performance of surveillance systems in other countries. Nareth et al., for example, found that hospital-based AFP surveillance in Cambodia is limited because a large proportion of the population is not seen at health centers (Nareth et al... 1997). In the case of Niger, other important limiting factors are: (i) community members' lack of knowledge about the possible link between a case of paralysis and a dangerous, communicable disease; (ii) the lack of access to health care, including the low number of clinics and health care workers; (iii) cultural beliefs that favor seeking out a local healer before consulting a nurse or physician; and (iv) the lack of training in disease surveillance among current health workers.

We recommend strengthening communitybased surveillance systems on the basis of the factors that we have outlined by using AFP surveillance as a case study. Strengthening surveillance would help to ensure the detection and reporting of disease cases and would complement current surveillance activities. It should be noted that community-based surveillance alone cannot improve the surveillance process without the support of well trained and dedicated health care staff, including epidemiologists, and minimum logistics needed to ensure communications between community members and district epidemiologists. In Niger, there are opportunities for community members to participate effectively in the process of AFP surveillance and to contribute to the detection and reporting of AFP cases.

Two essential steps need to be taken to establish the foundations of such participation. The first important step is to recruit, train, supervise and motivate a corps of community health agents. These community agents can play different roles, including conducting campaigns of awareness and motivating parents to report early suspected cases of AFP in their households. Community agents should also keep their eyes and ears open and report suspected cases on their own, especially when they suspect that parents would not, as a result of their cultural beliefs and/ or lack of access to transportation or communication with an epidemiologist.

The second important step is to develop linkages and collaborations among various community

opinion leaders and interest groups to improve the sensitivity of AFP surveillance at the peripheral and local levels. Traditional healers who treat paralyzed children, local midwives who deliver babies and follow their growth, secouristes who provide first aid, and community health agents who disseminate health information are all involved in providing health care. It would be useful for epidemiologists to partner these individuals, who are likely to encounter or know about AFP cases. Local healers, in particular, earn their living trying to treat diseases such as paralysis, and may find it disadvantageous to refer cases to the local clinics, thereby losing their clients. It is therefore important to find ways of reassuring them, perhaps through compensation, to turn them into reliable and effective allies. Providing rewards to community members who reported cases and to health workers who confirmed them was critical in the smallpox-eradication campaigns (Foster et al., 1980; Cutts et al., 1993). Similar examples with regard to the eradication of polio were given by de Ouadros et al. and Nareth et al. for South America and Asia, respectively (de Quadros et al., 1991; Nareth et al., 1997). However, compensation for community surveillance workers is a controversial issue on which there is no consensus among development experts.

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