Community participation and tropical disease control in resource-poor settings
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Community participation and tropical disease control in resource-poor settings

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1 INTRODUCTION

In 1975, the Executive Board of the World Health Organization and the World Health Assembly called for an international conference to address the conspicuous inequalities in health and health services between countries (World Health Organization, 1988). The 1977 World Health Assembly specified that the central social goal of WHO was a level of “acceptable” health that would allow a “socially and economically productive life” for all people by 2000, and called on nation states to work towards this goal. These issues were addressed at a meeting in Alma Ata the subsequent year, and the resultant Declaration of Alma Ata was to influence global and national strategies, policies and programmes for the next two decades. It emphasized the need to provide “Health for All” by collaboration between biomedical and traditional sectors, and encouraged approaches to health care that incorporated community participation and community development. Subsequently, social scientists assumed an increased role in the implementation of health care programmes, as they were required to generate relevant knowledge from which to assist the development of appropriate interventions within communities (e.g. Manderson et al., 1992).

The Declaration called for health care to be restructured: primary health care was to be the main focus of health systems and an integral part of social and economic development. It stated that “Primary health care requires and promotes maximum community and individual self-reliance and participation in the planning, organizing, operation and control of primary health care, making fullest use of local, national and other available resources; and to this end develops through appropriate education the ability of communities to participate” (World Health Organization, 1978). Community participation was thus presented as the principal means to ensure delivery of primary health care. Its importance, as Manderson et al. describe, rested “on two axioms: that the only way to overcome limited and unequally distributed resources to ensure Health for All is through the involvement of local communities in the prevention of disease and the treatment of the sick, and that without community involvement and responsibility, programmes will fail” (Manderson et al., 1992).

In the context of infectious disease control, community participation was conceptualized by writers such as Morely et al. (1983) to include the empowerment of individuals. Community participation, in this sense, was proposed as a means to increase people’s autonomy over health care. Unfortunately, little regard was given to whether communities were interested in participating in such activities. From their perspective, all that would be required of external agencies in order to encourage effective health care through community participation was that they provide a community with appropriate information about the disease and the correct prevention or control strategies (Rifkin, 1985; Brownlea, 1987; Manderson et al., 1992). Factors such as the resources available to very poor communities to organize themselves, their willingness to take an altruistic approach to disease control, and their view of health promotion activities and structures, were considered only in passing, or not at all. In addition, little attention was paid to the relationship between external motivators and community programme officers. Proposed primary health programmes were almost always developed without consultation with specific communities despite an increasing awareness that, with this kind of health structure, many inequalities were maintained, and often exacerbated, by the expectation that the poor should be responsible for resource deficits of governments.

There have already been arguments that community participation, as defined in the Alma Ata Declaration, has limited application in vector-borne diseases (Das, 1991). Although providers of primary health care have recognized the importance of good quality curative services to enable communities to participate in interventions and to adhere to treatment (Stone, 1992; Zakus and Lysack, 1998), it is not clear how to involve communities most effectively in strategies that address their needs. The reality is that most communities where vector-borne diseases are endemic lack institutional systems and structures to encourage people to participate in control strategies, and if they are present, they do not function adequately.
Although congruent with the goal of the Alma Ata Declaration, community participation for tropical diseases is more specific. Participatory activities are defined to ensure outcomes that will contribute to the overall aim of reducing disease prevalence, and consequently are predetermined to be consistent with the epidemiology of the disease and known interventions to reduce transmission. Hence, community participation in the control of vector-borne and tropical infectious diseases is a means to implement control activities in order to contribute to the overall goal of Health for All. Further, community participation is often implemented, not as an end in itself, but as a vehicle or mechanism to augment government activities and responsibilities. Depending on the vector-borne or infectious disease, community participation activities may be intermittent (such as bednet impregnation) or routine (regularly emptying bottles and tyres of water) and may be undertaken by either individuals or groups. Typically, the activities that are required in order to reduce transmission of disease, or to prevent severe morbidity or mortality, are determined externally. Participating communities have also been identified externally, on the basis of high prevalence of disease or perceived vulnerability. In addition, given that strategies to control vector-borne diseases (and health) are constantly improving, and policies revised and adjusted, it is clear that an external agency needs to be a critical partner to any community programme. Community participation in the context of vector-borne disease control, therefore, is very different from that described in literature that emphasizes (at least as an ideal) the role of community in both the conceptualization and implementation of health promotion and disease prevention activities.

Almost 30 years have passed since the Declaration of Alma Ata. Primary health care practitioners and planners, as well as academic writers, continue to draw on it discursively. There remains a strong commitment to primary health care as an objective, and to community participation as the ideal means to extend effective health care to remote and poor communities. However, pragmatic and tempered perspectives of this purpose have been realized (Morgan, 1993; Tatar, 1996; Morgan, 2001).

In this review, we highlight the tensions that exist between the ideal representations of what community participation can achieve, and the reality of its implementation in resource-poor settings. This review considers the historical evolution of ideas and practices surrounding community participation, as well as current perspectives and problems associated with it. Past reviews of community participation in tropical disease control have emphasized pragmatic issues: the relationship between income generation and involvement, attrition of volunteers, the involvement of key members of community, and the importance of health education to mobilize populations (Manderson et al., 1992; Service, 1993). Here, we examine debates surrounding community participation, its interpretation and application in tropical disease control, and identify knowledge gaps. We also draw on work conducted in tropical disease endemic countries, and explore how community participation has been implemented with respect to the control of vector-borne and other tropical diseases.
2 HISTORICAL ANTECEDENTS OF COMMUNITY PARTICIPATION

The attention paid to community participation as an essential component of primary health care and as a precondition to Health for All is historically situated. Many of the difficulties faced since 1978, when community participation was first introduced as a formal strategy, were rehearsed in public health measures some decades earlier (Madan, 1987; Rifkin, 1996). Yet previous experience of difficulties encountered while attempting to involve communities in disease control, and of sustaining such programmes over time, appears to have passed largely unnoticed, with few lessons drawn from earlier experience.

In the first half of the 20th century a variety of public health programmes were operating with some measure of what would later be called “community participation”. These programmes were not unique to a particular region. In tropical countries, the majority of which were colonies, public health programmes complemented curative services. Community involvement in some of these was successful, generally because the interventions with which they were linked were efficiently organized. However, broad-based interventions, including those that depended upon improved or changed living conditions, were somewhat less successful.

2.1 “Community participation” and colonial public health

In the first half of the 19th century, medical practice in both the industrialized centre of Europe and in their colonies, focused largely on the provision of curative services. However, from the mid-1800s, public health programmes were introduced to complement hospital-based services and to control infectious diseases. By the early 1900s, in tropical colonies as well as imperial centres, governments had established programmes to reduce infectious diseases, ensure potable water and sanitation, and promote maternal and child health. Primary health care services, delivered from aid posts, mobile units, and fixed rural health clinics, ensured that minimum medical services were extended to populations located at a distance from hospitals, and provided an institutional structure to respond to epidemics and deliver preventive and promotive health programmes. Indeed, Vaughan (1991) argues that colonial medical departments, “far from being obsessed with curative medicine,” embraced preventive medicine enthusiastically, particularly when disease outbreak might threaten the welfare of colonists and colonial economic endeavours. In order to encourage the prevention of disease, including vector- and water-borne diseases, various tactics, which are now associated with community participation, were implemented. They provided the foundation for, and experience of, community participation in public health programmes that followed.

British colonial history provides numerous examples of the ways communities were involved in the provision of public health services and primary health care. The techniques employed by British colonial administrators and medical experts during smallpox inoculation campaigns, for example, demonstrated the importance of establishing community compliance in public health programmes. In this case, children were used to facilitate live (arm-to-arm) transmission of the vaccine. Systematic vaccination did not occur until after 1870, when health authorities began to employ special-purpose vaccinators. In some Asian and African colonies, police assembled children on a given day, and prevented them from leaving until all had been vaccinated. These techniques were not always received with equanimity. In the Federated Malay States and Nyasaland, for example, there was considerable resistance to this practice, and desperate government officials were forced to seek the support of local leaders to encourage people to bring their children forward for vaccination (Vaughan, 1991; Manderson, 1996).

British efforts to reduce plague transmission in its colonies provide a second example of “community participation”. Throughout the colonial period, increased shipping and urban expansion created ideal conditions for sporadic outbreaks of plague. Initially, the response of governments was to reduce
transmission by isolating diseased people and their regular contacts. Local community leaders, who distributed information in the vernacular, supported this strategy. When the relationship between rats, fleas, and disease was discovered in the late 19th century, rat catching was introduced and promoted as a community activity (Manderson, 1996). The bounties offered for corpses, and the grisly rat pyres that followed, captured the imagination of local youths and some women. In the Congo and Colonial Malaya, a reward system was introduced to encourage people to catch rats. In these territories, mass education campaigns and public mobilization centred around pyres of rat corpses (Vaughan, 1991; Manderson, 1996). The implementation of these “community participation” programmes was by no means egalitarian. In Uganda, diseased indigenous people were put in isolation, while European residents were persuaded to catch rats.

Dutch researchers were sceptical of British research on the cause of plague, and this influenced their response to epidemics. The primary means of controlling plague in Indonesia - evacuation, fumigation and roadblocks - were met with considerable resistance from affected populations. Dutch officials associated the plague with poor living conditions, given that housing improvements were accompanied by a decline in incidence of this disease (Hull, 1987). During the late 19th and early 20th century, the Dutch government began to train Javanese hygiene mantri. The latter worked with villagers to improve living conditions, hygiene and sanitation. According to Hull, these mantri were “prototypes of the modern primary health care worker” (Hull, 1987). The Rockefeller Foundation promoted similar tactics in British Malaya, and also employed mass treatment, classroom education, the wearing of shoes, and latrine construction, maintenance and use latrines in its public health programmes in Asia, Pacific and the Americas (Farley, 1995; Cuerto, 1995).

Malaria also provided an early example of community involvement in disease control. Then as now, interventions included chemotherapy (quinine), house screening and the elimination of breeding sites (Farley, 1995). By the 1930s, British Malaya already possessed an extensive bureaucracy for malaria control, with dedicated government agencies working in collaboration with sanitary boards, a research institute, and owners and managers of rubber estates. Vernacular health education material was produced. This focused on mosquito bite avoidance, early diagnosis and treatment, and the importance of environmental management. Labourers were recruited to clear jungle, undergrowth and drainage ditches, and distribute oil over bodies of water (Manderson, 1996).

Community participation was, in part, conceptualized as a mechanism to encourage the “natives” to embrace a biomedical perspective on disease, and to adopt biomedical (and colonial) practices. In this regard, the rhetoric of colonial public health was very different to that employed since Alma Ata, with community participation presented as a mechanism to bring people to biomedicine, rather than - as now - a means for communities to identify their own health priorities and implement appropriate strategies on that basis.

2.2 Community development

Approaches to disease control characteristic of the colonial period persisted in newly independent states after World War II. During the 1940s and 1950s, most health experts assumed people in the Third World would readily accept “superior” biomedical knowledge and technology (Stone, 1992). These health experts also regarded “traditional” (that is, non-biomedical) values as obstacles to health improvement and development (Ugalde, 1985), although only as a relatively short-term problem – over time, “native” people would discard these in the face of superior Western scientific knowledge. This did not prove to be the case. In the 1970s, acknowledgement of the failure of colonial and post-colonial regimes to establish sustainable health programmes, and of persistent inequalities in health status, health services and care in newly independent countries, culminated with the meeting at Alma Ata (Hardiman, 1986; Rifkin, 1985). At Alma Ata, participants expressed their concern at the continuing poverty and poor health indicators in developing countries, and at the apparent inability of orthodox models of health service to address these. They were also concerned by the realization that many structural barriers to primary health care and community participation persisted despite efforts to remove them.
The concept of community participation partly evolved, therefore, in response to criticisms of the community development movement. The movement had been accused of excessive bureaucracy and of imposing homogenous programmes on diverse peoples on the assumption that these were universally appropriate. Contemporary ideas about community participation and development were embraced because it was thought they had the potential to liberate the powerless, and thus to ensure genuine participatory development by all people (see Midgley, 1986). Subsequently, the United Nations adopted these popular concepts and incorporated aspects of them into the Alma Ata Declaration.
The inclusion of community participation in the Alma Ata Declaration was primarily justified on the grounds of expense – it was thought that this provided the only affordable means of extending good quality curative services throughout developing countries. Community participation appealed to national and provincial governments, including health and political sectors, because it had the potential to relieve at least some state responsibility for providing peripheral health services (White, 1982; Krogstad and Ruebush, 1996). However, acceptance of the Alma Ata Declaration model of community participation, which called for communities to identify their own needs and find ways to satisfy them (Stone, 1992; Morgan, 2001), was not universal. This approach was regarded as “unrealistic and unimplementable” (Ugalde, 1985).

The Alma Ata Declaration stated that primary health care must be culturally acceptable for community participation to occur. If it were not, target populations would not use primary health care facilities, nor participate in preventive, educational, curative and referral programmes. If target populations did not participate in these ways, primary health care measures would fail. However, although the phrase “culturally acceptable” was often used, it was not defined, and little attention was paid to cultural or institutional aspects of health policy, or to how these might interact with structures of government.

Ten years after the Alma Ata meeting, WHO and UNICEF led a decision to examine and review progress towards Health for All by the Year 2000, and if necessary, reorient strategies. A review meeting was held at Riga, USSR, and findings from this meeting were presented at the 41st World Health Assembly. The review drew attention to significant progress that had been made towards Health for All in 1988, and acknowledged the attention national governments had paid to health conditions. However, despite government commitment to this endeavour through the formulation of national policies and some practical attempts to introduce or expand primary health care, the review also noted that there was little capacity for developing and sustaining effective programmes. The review committee noted that bureaucratic inefficiency, lack of managerial experience, and weak support systems for primary health care had defeated integration and decentralization programmes (World Health Organization, 1988). Disparities in the health status of populations and in the distribution and quality of health services had increased, both between and within countries, during the first decade after Alma Ata.

Specifically, the review committee recommended improvement in:

- Programme management skills at the level of community health facilities and other local structures, including improved health systems and services, community health facilities accountable for community health, improved coverage of primary health care, and the collection and analysis of local data to evaluate services and coverage.
- Support for health personnel who carry out primary health care.
- A shift from selective to comprehensive or integrated primary health care, with increased investment in health development (i.e. health promotion), and communities actively involved in planning and implementation.

The double burden of disease (infectious and chronic, non-infectious diseases) among the urban poor and marginal populations in rural areas added to difficulties encountered in the practical application of primary health care to these populations (see also Kekki, 2003). Preventive and curative strategies to address these problems were not accessible at the primary health care level. Debate in academic literature regarding primary health care and community participation prompted research projects aimed at encouraging a “bottom-up” approach (Rifkin, 1985; Brownlea, 1987; Manderson et al., 1992). Others argued that multiple agencies and sectors – political, agricultural, industrial, educational, housing, public works and media – needed to be involved in primary health care to attain the goal of Health for All (Midgley, 1986; World Health Organization, 1988; Stone, 1992; Espino, 1999). They also argued that reform of these sectors and agencies was required at both national and local levels.
Part of the difficulty in reviewing community participation is the variable use of the terms “community” and “participation”. The phrase “community participation” encompasses a spectrum of approaches and strategies. In health promotion literature, community development and community participation have been presented as strategies for social development. These give particular emphasis to ideals of social justice, and advocate change in social, political and economic systems. At one extreme, community participation is regarded as essentially democratic, that through dynamic and evolutionary processes achieves equity and, ultimately, social development (Rifkin, 1996). At the other extreme, community participation is characterized as a time-bound strategy that obtains Health for All through activities introduced at the level of primary health care. These parallel concepts of community participation evolved during the period preceding the Alma Ata Declaration. Each incorporated community participation as a core strategy toward their respective ends: social equity via social development and health for all via primary health care.

4.1 “Community” in vector-borne and tropical diseases

The Alma Ata Declaration conceptualized a “community” to be a cohesive unit of individuals bound by characteristic economic, socio-cultural and political relationships, each with common problems and needs (Jewkes and Murcott, 1996). This particularly idealistic notion of community is not consistent with the way community is defined epidemiologically, that is, as a group of people vulnerable to infection. It also fails to acknowledge differences in the goals and resources of individuals (or groups), even within so-called “communities”. Other definitions of community, such as that described by Patrick and Wickizer (1995), include place, social interaction (incorporating social support and shared perceptions, beliefs, knowledge and goals, thus with national and international scope), and political and social responsibility. This definition allows for “boundaries [that] shift with the nature of the need and the varying involvement of individuals and collectives” (Patrick and Wickizer, 1995). Zakus and Lysack (1998), base their definition of community on two fundamental criteria: locale, and a sense of belonging through shared interests, values and identity. Their underlying assumption is that cleavages in a given community (caused by class, kinship or political affiliation, for example) may be overcome by these fundamental qualities of “community”, so that common goals may be achieved.

In the context of tropical disease control, a geographical definition of community has dominated (Manderson et al., 1992). Use of this geographical emphasis has been pragmatic because disease control programmes have often been implemented through primary health care services, which are also defined with reference to specific geographic locations.

The inclusion of locale in a definition of “community” for disease control purposes is useful, since in epidemiological terms, vector-borne and infectious diseases are transmitted and concentrated geographically. Many tropical diseases are transmitted by a vector under specific ecological and environmental conditions and, by definition, are infectious, so that transmission presupposes both infected individuals and hosts in a given environment. The geographical boundaries of the vector and prevalence of disease are used to identify groups at risk of, or vulnerable to, infection, who are subsequently targeted for interventions. However, the emphasis on locale as a defining characteristic of “community” in tropical disease research and control programmes has meant that little attention has been paid to non-geographical features or factors of any given “community”. These include administrative factors (such as the hierarchical relationship between village, town and province), factors relating to culture and social structure, and psychological and other issues that influence the perceived needs and experiences of people living in a “community”. Various commentators have noted that geographical communities are held together by social and political systems (see Patrick and Wickizer, 1995) and are influenced by social, political, economic and cultural factors (Midgley, 1986; Oakley, 1991); this emphasis ignored increasing diversity in localized groups of people and subsequent displays of ruptures of interest that are features of contemporary urbanized and industrialized settlements.
4.2 Means (towards Health for All) or an end (in itself)

The authors of the Alma Ata Declaration presumed that, in order to fulfill their role as participants, community members would need to be empowered. With empowerment, people would be able to reflect on their health needs, and make appropriate (i.e. efficacious) plans and decisions regarding those needs (World Health Organization, 1988; Zakus and Lysack, 1998). However, even with this acknowledgement, different groups had diverse understandings of the role of community participation and the specific form that empowerment would take.

Approaches to community participation are exemplified by regarding community participation as an adequate **end** for programme initiatives and as a **means** toward a purpose other than participation per se. Community participation is an **end** when it empowers communities to “make choices concerning health services through effective control over these programmes” (Woelk, 1992; Rifkin, 1996). Specific health outcomes are not pre-determined by programmes that follow this concept of community participation. It is thought that a community, when properly empowered, will be able to adequately identify and address its own health needs. This particular approach to community participation emphasizes democratic practice: individuals and societies are conceived as having a right and duty to participate in decisions affecting their lives (Hastings, unknown). It presupposes the existence of common purpose within communities, and a shared perception of current health status and desirable outcomes.

Advocates of this approach to community participation emphasize the importance of processes of participation (Tatar, 1996; Botes and Van Rensburg, 2000), although the argument risks circularity: community participation is only possible **with** empowerment and at the same time, it **produces** empowerment.

The means approach to community participation is usually adopted in programmes for tropical disease control. Here, the ultimate end of any programme is to control a specific disease; community participation is a means to achieve this, but not an end in itself. This pragmatic approach to participation, often adopted by governments and disease control programmes, allows for participation to be either contributive – of labour, cash or materials in predetermined programmes, or organizational – involving the creation of structures to facilitate participation (Woelk, 1992). These definitions regard participation as a means to an end, which entails more than “comment and advice” (Tatar, 1996). Contributions aspects of participation are evident when a community health worker prepares a malaria blood film for microscopy at the rural clinic, and organizational aspects when a village health worker organizes villagers for bednet insecticide treatment. The overall effects of such health interventions are the result of collective or cumulative action, which in the context of community participation involves both community members and “outsiders”, such as government officials or project personnel.

4.3 Facilitatory communities

Community participation (as a means or an end) attributes a functional quality to the “community” – wherever “the community” is or whatever forms it takes. This is, obviously, because in each case a “community” is defined in relation to an ultimate aim, whether it is control of a specific disease or a particular social circumstance (such as community empowerment). As such, all community participation programmes are **facilitatory** – that is, they are intended to facilitate a particular or general goal, aim, or end. In the process of conceptualizing such programmes, the “community” is often regarded as standing outside a specific initiative; the goal of a programme is to incorporate or include this “community” within its structures and processes. Although this is a conceptually convenient, and on occasion, efficacious way to regard “communities”, we would like to propose that the practice of regarding “communities” as standing apart from, and existing separately to, specific community participation initiatives in fact conceals the relationship between the “community”, the programme, and the external agency.

Nevertheless, despite diversity in what comprises specific “communities”, as well as in their form and function (if any), the presumption of virtually all community participation programmes is that they will
augment, or add to, a community that existed prior to, and exists independently of, the specific programme intended to change it. The argument that community participation produces sustainability is based on this presumption – once the practices of the “community” are altered, the agency that was integral to the programme can withdraw; because the “community” is separate from the agency, it will continue to function even without input from the agency.

Unfortunately, this has occurred very rarely. In most cases, when the agency withdraws from the community, the processes introduced by it fail to perpetuate. Time and again, sustainability in community participation initiatives has only been achieved with sustained involvement by the external agency. We may enquire, then, why this should occur. In a very real sense, community participation programmes do not augment “old” communities – they create new ones. These created communities may co-exist with the old, indeed, on the ground, they may appear to be identical. But the facilitatory (“new”) community is sustained by the external agency, as well as by members of the “old” community. When the former is removed, the community often loses the functionality it acquired while the external agency was present. Thereafter, the “new” community ceases to exist, but the “old” community persists, if in a slightly changed form (if any “community” existed before the programme was introduced). Thus, in most cases, the ideal of community empowerment by which communities effectively, and autonomously, assume responsibility for their own health needs, is flawed. Sustainability requires the ongoing involvement of external agencies, which are, in fact, integral members of the “created” community.

4.4 Participation

Community participation may involve a spectrum of processes, including (but not restricted to) organization, planning, evaluation, cooperation, and contribution of time, labour, and/or resources by the host community (Ahmed, 1978; Woelk, 1992). Community participation is usually conceptualized as a process by which people (i.e. members of communities) individually or collectively assume increased responsibility for assessment of their own health needs, and once these are agreed upon, identify potential solutions to problems, and plan strategies by which these solutions may be realized (Bermejo and Bekui, 1993). Often, during implementation, specific organizations must be created and/or sustained in order to achieve these goals.

Community participation is often viewed as a means by which people can meaningfully participate in activities that have a positive impact on their collective health, and in the process, transfer to them a sense that they can solve their problems through careful reflection and collective action (Zakus and Lysack, 1998). In practice, members of communities only participate in some of these processes. Local institutions, community leadership structure and the availability of the necessary resources – knowledge, time, cash and contributions in kind – determine who participates and how (Bermejo and Bekui, 1993). Policies and guidelines for vector-borne and tropical disease control programmes often emanate from central or national offices. National (or even regional and provincial) health offices often perceive the needs of communities differently from communities themselves (Woelk, 1992), so that often, and despite the rhetoric of self-determination, communities are compelled to implement strategies determined independently of them. In most vector-borne disease control programmes, widespread participation by community members has been limited and remains the responsibility of the health sector.

Characterizations of community participation also emphasize cultural acceptability in the application of appropriate technological interventions applied at the “periphery” (World Health Organization, 1983). However, these are not always appropriate for disease control – often there is little choice for programme administrators in terms of the form of intervention, and there are considerable risks where interventions are inappropriately implemented.
5 PREVENTION AND CONTROL OF TROPICAL DISEASES

The most important justification for the Alma Ata Declaration of Health for All, and its emphasis on community participation in primary health care, was its affordability compared with conventional, vertical, programmes. Vertical disease control programmes were to have come to an end with the Alma Ata Declaration, following general acknowledgement that the expenses of vertical programmes, such as recurrent costs, were not affordable as decentralized schemes (Gish, 1992). New approaches, aided and facilitated by community participation, were expected to enhance the effectiveness of tropical disease control in endemic areas.

Another justification for community participation in tropical disease control was its anticipated potential for meeting the goals and objectives of national control programmes. The degree of community participation required was understood to be variable, depending on the characteristics of specific interventions (Bermejo and Bekui, 1993; Service, 1993). For example, behavioural changes (e.g. bednet usage) required a high degree of participation and practices to be sustained over time, whereas vaccination (e.g. BCG) required low levels of sustainability with community participation as a one-off event. The economic and epidemiologic advantages to be derived from (successful) community participation programmes were likely to be greater where behavioural change occurred, and accordingly, there was increased advocacy for the integration of environmental management and community participation into measures for vector control (World Health Organization, 1983; Knudsen and Sloof, 1992). Community participation was particularly favoured, and possessed the greatest potential benefit, in strategies requiring changes in environment management, sanitation and behaviour (Knudsen and Sloof, 1992; Manderson et al., 1992). Consequently, community participation was conceived to be more crucial in programmes aimed at the control of disease transmission than in those favouring an exclusive curative approach (i.e. to control morbidity) (Tanner et al., 1986).

In the following sections, we present published articles where community participation was employed in various forms for the following tropical and/or vector-borne diseases: African trypanosomiasis (vector control through tsetse fly traps), Chagas disease (improved housing conditions), dengue (elimination of Aedes aegypti breeding sites), filariasis (chemotherapy through community members versus health services), leishmaniasis (community initiatives for treatment), leprosy (self-help groups for wound care), malaria (community organizations for mass drug administration and a health development programme), onchocerciasis (community directed mass drug treatment), schistosomiasis (multilateral approach to health education), and tuberculosis.

5.1 African trypanosomiasis

African trypanosomiasis (sleeping sickness) is principally caused by two subspecies of the complex Trypanosoma brucei – T. b. gambiense and T. b. rhodesiense. The former, found in West and Central Africa, causes chronic infection in the host and symptoms may not emerge until years after infection. The latter, found in East and Southern Africa, causes an acute infection that may be identified a few weeks after infection. If left untreated, both forms of the disease are fatal. African trypanosomiasis is responsible for significant economic costs in countries where it is endemic. To date, control programmes have focused on diagnosis and treatment of the disease in humans, and on elimination of the insect vector, the tsetse fly (Glossina sp.). Diagnosis and treatment have been the most effective methods of control since the early 20th century (Joja and Okoli, 2001).

Community participation has long been regarded as an appropriate measure for vector control, for tsetse fly traps. The maintenance of insecticide-impregnated traps involves treatment every one or two months, and has presented difficulties (Gouteux et al., 1987). In the 1980s, community participation was employed in the Congo for the control of African trypanosomiasis using traps that did not require insecticide treatment. Although these traps were effective, results were equivocal. Gouteux et al. (1987) argued that interest was not sustained where tsetse fly density was low, local knowledge of the disease was poor, and village health committees were weak. They argued that vector control had to be
incorporated within primary health care programmes to maintain their efficacy. In a later study, Leygues and Gouteux (1989) described how indigenous beliefs in supernatural causes for disease also undermined the effectiveness of the programme, as local people regarded tsetse fly control as inappropriate and ineffective.

The case study presented illustrates the role of community understanding of vector control measures in facilitating their involvement in these measures.

**Community action to curb sleeping sickness in Southern Sudan**

In the 1990s, South Sudan experienced a sudden increase in African trypanosomiasis (*T. b. gambiense*). In 1997, public health officials adopted an integrated approach of mass screening, treatment, and community-based vector control, in Tambura County, South Sudan. The Cooperative for Assistance and Relief Everywhere (CARE), the International Medical Corps, and the US Centres for Disease Control and Prevention (CDC) conducted surveys to determine the seriousness and prevalence of the outbreak. High rates of infection were discovered (up to 20% in some areas), and a public health response, incorporating screening, treatment and prevention, was developed. Community participants used traps designed specifically for them, similar to those described by Leygues and Gouteux (1989). National health officials were trained in tsetse fly control techniques, and subsequently trained others.

Within communities, volunteers were trained how to construct, maintain, and place traps. “Supervisory trap monitors” were given bicycles to enable them to collect and deliver captured flies to health officials, who monitored fly density in collaboration with CARE. Thus, county health officials, community groups, and CARE shared responsibility for the project.

Between 1997 and 2001, 3250 traps were constructed and placed in areas of high tsetse fly density. During this period, the average number of flies caught in each trap dropped significantly, from 25 flies per trap per week to an average of just 3 by 2001. This community-based programme acted in concert with an “aggressive programme to identify and treat persons with sleeping sickness,” so that the prevalence of sleeping sickness was reduced from 9% in 1997 to 2% in 1999. The authors noted that “although it is not possible to document a cause-and-effect relationship between the trapping activities and the reduced prevalence of infection, it is reasonable to postulate that the trapping project has increased local interest in monitoring the disease and participating in prevention and treatment efforts”.

The success of the initiative was attributed to a number of factors. Firstly, the traps were easily constructed from local materials, easy to set up, and easy to maintain. Secondly, the community volunteers in this programme were largely recruited from traditional birth attendants, and the involvement of women’s groups in the programme was described as crucial to its success. Volunteers also benefited from increased status within the villages as a result of their activities. Finally, the consultation and education of villagers that took place before the intervention were crucial, as “when people understand how a health problem occurs and have some economical and practical means to combat the problem, they are likely to raise their level of participation in efforts to increase their own well-being and the well-being of villagers yet to be born”. 
5.2 Chagas disease

Chagas disease is a parasitic infection transmitted by a triatomine insect, and occurs only on the American continent. The insects live in houses, typically in cracks in walls, roofs and floors. At night the insects feed, depositing their faeces and parasites on humans. Control measures tend to focus on infestation identification, elimination of the insect vector, and housing improvement (or housing reconstruction) to reduce habitats favourable to insect vectors. Chagas’ disease is estimated to be extremely costly to the economies of states where it is endemic due to significant losses from absenteeism and lost production (Moncayo, 1997).

The effectiveness of housing improvement in the control of Chagas disease means that, in programmes where housing improvement is prioritized, community participation strategies are likely to be very successful, and coordinate with broader public health measures. In all models of community participation for the control of Chagas disease, the state or respective health agency maintains a role in the control of disease. Typically, this role involves the provision of one or more of the following: subsidies or materials for the construction and/or upkeep of houses; measures for detecting the triatomine vector (community education, devices, skilled personnel); and insecticides. By and large, these programmes have been successful, but difficulties have been encountered in the provision of control measures to dispersed settlements and communities. The active, and often necessary, participation by the state or a state-controlled body in the provision of resources for Chagas’ disease control may prove disadvantageous to programmes in states where fiscal crises emerge – the recent collapse of the Argentinian economy may well prove a case in point.

Community participation in the control of Chagas’ disease tends to focus on two phases of intervention, referred to earlier – provision of better housing and detection of the insect vector. Health services personnel or community volunteers can perform chemical eradication of the vector with insecticides provided by the coordinating health agency. Community participants typically provide labour for housing improvements, and contribute to the cost of materials, although these costs are typically subsidized by the state or health agency. Efforts to reduce costs associated with the improvement of housing include the provision of advice to participants on the use of appropriate indigenous building materials and housing techniques that are conducive to vector control.

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Community participation in the control of Chagas’ disease: examples from Brazil, Venezuela, and Bolivia*

Programmes for Chagas’ disease have traditionally employed passive, rather than active, control methods. Most control efforts have employed a model derived from the vertically-structured malaria model, using government-sponsored teams to spray homes with insecticide, and requiring community members only to comply with treatment of their homes.

Brazil

In Brazil, control measures centred on the control of insect vectors by application of insecticides. Initially this was implemented through a vertically-structured campaign, in three phases:

- Preparatory phase (mapping of treatment area).
- Attack phase (spraying of all houses and peridomestic structures).
- Consolidation and surveillance phase.

The first two phases of this programme were implemented in the late 1980s, and were largely successful in reducing incidence of the vector, and subsequently reducing recognized cases of acute disease. However, political changes in Brazil concomitant with this programme favoured the introduction of community participation measures in the consolidation and surveillance phase. According to Bryan et al., these changes centred around emerging social and ethical principals of health and equity for all rather than economics driven.
The Brazilian approach to community participation centred on: 1) the introduction of local health agents, each supervised by local (community) and national groups, and 2) the encouragement of community vector surveillance by community leaders, local teachers, etc. Essentially, communities became responsible for house surveillance and identification of potential infestation. If infestation was detected, the local health agent was called in to confirm presence of the vector, and if necessary, apply insecticide to the residence. Local health workers also facilitated the provision of broader health services to the community. The cost to the Brazilian government was estimated at US$ 5 per house (1994). The approach was successful in eradicating infestation by *Triatoma infestans* from 85% of 711 municipalities.

**Venezuela**

Programmes for control of Chagas’ disease in Venezuela encountered different circumstances. The main insect vectors were not restricted to domestic environments, as was the case in Brazil. Palm trees were a common habitat for Venezuelan insect vectors, and as palm leaves were often used as roofing materials, domestic infestation was high. These conditions compromised the effectiveness of insecticide programmes. The Venezuelan Ministry of Health (MOH) considered housing improvement the best means to control transmission of Chagas’ disease. A housing programme, using local labour and construction materials, was introduced in 1958. This was initially successful, but eventually faltered when construction costs rose due to the use of pre-fabricated materials for housing. The population originally targeted for intervention could no longer meet the minimum income criterion that was prerequisite for home ownership.

In 1976, the MOH and WHO established a cooperative housing improvement project after conducting research to find local construction materials that were affordable, locally available, and appropriate for the provision of adequate housing. Effective methods of house construction were also investigated. A programme was introduced whereby community participants were trained in construction techniques, so that in due course building programmes could be sustained in communities without the need for extensive governmental assistance. In 1985, the programme was modified to include measures for community education on sanitation and hygiene, and introduce dialogues with community members on strategies to finance local costs. Ultimately, a system of credits was devised between local populations and the state to enable community members to purchase building materials. By 1994, improvements were seen in the provision of housing, which cost community members an estimated US$ 1300 for a new house, and US$ 150-300 for improvements to existing houses.

**Bolivia**

In Bolivia, insecticide treatment and housing improvements were employed with community education measures. These controls were coordinated by the National Chagas’ Disease Control Programme, which appointed regional medical supervisors to: coordinate local community involvement in the programme and resource distribution, and provide serological and entomological testing and research.

Communities were required to select local persons to serve as health promoters. They received appropriate training and were each responsible for 40-80 households. Their job was to visit the households, educate the occupants on appropriate health practices, and inspect the buildings for signs of infestation. An important function of the health promoter was to “motivate the family to execute control measures within their homes” – specifically, to encourage housing improvement.

Housing improvement was implemented in stages. Each household was required to complete each stage to the health promoter’s satisfaction in order to receive additional assistance. Construction materials were provided from donated materials, and construction used local labour in consultation with a building expert. Insecticide was applied when construction was completed. Health promoters instructed families on appropriate means to maintain vector-free homes. If reinfection was discovered, insecticides were reapplied to the house. Sustainability of this programme was dependent on the support of state organizations and the assistance of donor agencies.

* from Bryan et al., 1994
5.3 Dengue

Dengue is caused by four related but distinct virus serotypes transmitted by the day-biting female Aedes aegypti mosquito (also Aedes albopictus). Infection results in an illness that ranges from a mild febrile episode to fatal hemorrhagic disease. The main challenges facing programmes for dengue control are to reduce Aedes breeding sites, and to sustain the effect of short-term interventions by community participation (Leontsini et al., 1993). Since the 1970s, epidemics of dengue have become widespread and disease has appeared in countries throughout the Pacific, South-east Asia, and the Americas (Gubler and Clark, 1994). Disease severity has increased where new serotypes have been introduced. Reasons for the increased incidence of dengue include rapid urbanization and increased air travel (Gubler and Clark, 1994). With respect to the former, water and sanitation systems are unable to cope with increased demand, and household responses to the lack of water supply create habitats for the vector.

Reduction of the vector is of central importance to dengue control. Although campaigns to eradicate Aedes aegypti in the 1950s and 1960s (ostensibly to control yellow fever) were effective in Central America, South America and the Pacific, these programmes were discontinued in the early 1970s; by the end of this decade, dengue had re-emerged (Lloyd et al., 1994). In all dengue initiatives, the role of an external agency (usually the state) is crucial as a means to instigate change through health education, and through proactive recruitment of community assistance (Gubler and Clark, 1994). Most community participation programmes have focused on eliminating domestic repositories of the mosquito vector by ensuring that water catchments are free of Aedes, and emptying water from discarded rubbish, old tyres, cans, etc. In order to encourage community compliance, health committees are usually formed to develop and deliver health education campaign messages (Lloyd et al., 1994). Many of these programmes have attempted to introduce methods for the control of the mosquito vector without the use of insecticides (Knudsen and Sloof, 1992), proposing what Marzochi (1994) referred to as an ecological control model.

**Dengue Control in Merida, Yucatan, Mexico***

Lloyd et al (1994) conducted a study on community education to reduce the incidence of habitats for Aedes aegypti in Merida. The researchers hoped it would lead to behavioural change within the community. Members of the community were involved in the development of educational material, and the means by which it would be distributed.

People were asked what their understanding of dengue was, how serious they considered it to be, and how they prevented and treated the disease. The researchers sought contextual information from their informants, including information on other febrile illnesses, biting insects, and ways that these were controlled. Finally, the quantity and type of containers surrounding people’s houses were categorized according to usage (whether they were considered disposable or not) and actual/potential larval status. Recommendations were prepared when this programme component was completed. The research team recruited community groups (formed for the research) to educate the wider community on ways and means to control Aedes aegypti. Suggestions for appropriate educational messages and materials were provided by the groups, such as the use of loudspeakers mounted on a vehicle, pamphlets, posters, television and radio slots, and fining people who did not keep their patios clean. It was decided to distribute the educational material door-to-door, and the members of the community groups visited each household twice, to distribute pamphlets and answer people’s questions – taking care to listen carefully as they did so. This was considered to be more successful than home visits that had occurred in the past, as previously “messages delivered during house visits by municipal vector control personnel were delivered very fast, such that parts of the message were unintelligible”.

After six months, the intervention and comparison groups showed significant differences in the mean number of containers positive for Aedes aegypti per household, and in the number of potential breeding sites per household. However, the researchers noted the effectiveness of such programmes in the long term was likely to be dependent on “whether the residents believe that the government in responding to their needs, such as providing garbage collection on a routine basis”. “If community participation is viewed as a means to shift responsibility and costs from the government to residents without the provision of services to support residents in their ability to carry out the recommended control measures, the prospects for sustainability may not be realistic”.

*from Lloyd et al., 1994
5.4 Filariasis

Filarial worms lodge in the lymphatic system and produce vast numbers of microfilariae that circulate in the blood. These are ingested by female *Culex sp.* mosquito vectors, and are subsequently transmitted to other human hosts. The disease is difficult to detect during the early stages of infection. Over time, the adult worms may block the lymphatic system, causing the characteristic swelling of arms, legs, and genitalia in those chronically infected (lymphoedema). In addition, kidney function may be compromised. Treatment is comprised of mass anti-filarial drug administration to all members of a community, often without specific diagnosis of infection. A number of community participation programmes focus on the transmission of filariasis; preventative strategies focus on mosquito control, with chemotherapy employed for the treatment of infected persons.

A comparison of community and health services in the delivery of filarial drugs in Tamil Nadu, India*

A research project was undertaken in Tamil Nadu, India, in 1998/1999, to compare the effectiveness of two methods for delivery of antifilarial drugs. The methods compared were community-directed treatment (ComDT) and health services treatment (HST). In the case of the former, communities were recruited and given responsibility for drug distribution; in the case of the latter, the existing health services delivered chemotherapy to rural populations. Two similar populations, with similar levels of health services facilities, were selected for the study.

Meetings with community leaders and members preceded the implementation of ComDT. Voluntary health nurses informed those assembled of the advantages of participation in the drug distribution project. Communities were responsible for selecting drug distributors, the time at which distribution would occur, and the means by which this would be achieved. Voluntary health nurses educated drug distributors (selected from the community) on the proper use of medication, and on more general information e.g. mode of transmission of filariasis. The HST component of this programme was managed and implemented by existing public health centres; diethylcarbamazine (DEC) was provided by state level administration.

Qualitative data indicated that the commitment and active participation of community leaders in ComDT villages was generally inadequate. Many community members felt this work was properly the responsibility of primary health care (PHC) workers and government employees. Health workers were of the opinion that, as community leaders were often wealthier than other villagers, they were more interested in politics, business, and occupational activities than they were in activities for general welfare.

The researchers found that distribution by the HST approach was more effective than ComDT. Under HST, a greater proportion of people complied with DEC treatment, which was crucial given that the proportion of population covered is an important determinant of lymphatic filariasis elimination. The effectiveness of ComDT was also compromised by lack of knowledge about filariasis in the community, the poor response of community leaders to the ComDT programme, and the reluctance of people to accept drugs from community-appointed drug distributors. Tensions between drug distributors and villagers centred around conflict in caste and group identification. Community members did not consider drug distribution to be a high priority, and were more interested in the provision of basic needs: adequate drinking water, roads, and schools. Overall, community members felt it was the job of the PHC services to distribute drugs.

*from Ramaiah et al., 2001
5.5 Leishmaniasis

Leishmaniasis is caused by several different species of protozoa (Leishmania sp.), and is transmitted by the bite of female phlebotomine sandflies. The clinical symptoms of the different parasites are variable; they include visceral leishmaniasis, characterized by weight loss, irregular bouts of fever, enlargement of the spleen and liver, and anaemia; mucocutaneous leishmaniasis, leading to partial or total destruction of mucous membranes of the nose, mouth and throat; and cutaneous leishmaniasis, producing ulcers on exposed parts of the body, scarring, and on occasion, serious disability. The disease is most prevalent in subtropical and temperate regions, particularly in developing countries. Epidemics of visceral leishmaniasis cause mortality, and other forms of leishmaniasis may result in social stigma and disability. Productivity and development are severely hampered in places where leishmaniasis reaches epidemic levels.

Recently there have been resurgences of visceral leishmaniasis in Africa (Sudan), South America and South Asia (Nepal, India). In India, this has been attributed to the decline in vector control (residual house spraying) for malaria. Although case detection of leishmaniasis is limited by the non-specific signs and symptoms associated with infection (Boelaert et al., 2000; Zijlstra and El-Hassan, 2001), health personnel in some affected areas have developed a case definition of visceral leishmaniasis which they use as a basis for starting treatment. Confirmatory diagnostic procedures (such as splenic aspiration) cannot be applied in rural areas due to insufficient resources and skilled personnel (Boelaert et al., 2000). Adequate control of visceral leishmaniasis is highly dependent on case detection, treatment and individual protection through vector control, in conjunction with strategies for house-spraying and use of impregnated bednets (Boelaert et al., 2000). In areas where sandflies bite indoors, house-spraying decreases the risk of cutaneous leishmaniasis in household residents (Davies et al., 2000). Untreated bednets also have a protective effect at the individual level (Bern et al., 2000).

Current available drugs for the treatment of visceral leishmaniasis are either toxic (the antimonials) or expensive (amphotericin B) and require hospitalization. Recently, oral treatment with miltefosine was registered in India; however, the costs of treatment make the drug inaccessible to the population most affected by the disease.

Patients’ associations for the control of leishmaniasis in Peru*

The people of Cuzco region, Peru, provide an extraordinary example of community participation in tropical disease control which has had a significant effect on the incidence of mucocutaneous leishmaniasis in the area. From the early 1970s, people in the altiplano highlands in Cuzco migrated to the forest area of Madre de Dios, after gold deposits were discovered there. Madre de Dios is an endemic zone for leishmaniasis, and from the 1980s onwards, cases of mucocutaneous leishmaniasis increased markedly here. Although most people contracted leishmaniasis while working in Madre de Dios, mucosal lesions often did not appear until the seasonal workers had returned to their homes in the mountainous areas of Cuzco.

Leishmaniasis was declared an occupational disease in Peru in 1975, and treatment was to be provided free of charge to people who worked in the forests. In practice, however, drugs and financial compensation were not made available to people who suffered from the disease. In 1983 in the town of Sicuani, a response of people who had contracted the disease was to form patients’ associations, which recruited members with the support of several institutions. The Catholic Church supplied them with drugs and publicized their activities on a local radio station. Over the next ten years, eight more patients’ associations were established in the region, representing 1648 members.
5.6 Leprosy (Hansen’s disease)

Leprosy is an infectious, chronic disease caused by *Mycobacterium leprae*. The disease is characterized by disfiguring skin lesions, peripheral nerve damage, loss of feeling in skin, weakness of muscles, and progressive debilitation. People often damage their hands and feet as they cannot feel them. Sustained, frequent damage in this manner eventually leads to loss of use of the affected limb. Leprosy can be treated by multidrug therapy (MDT), although some drug-resistant strains have emerged.

Programmes employing community participation are aimed at early diagnosis and treatment, and involve community education, diagnosis of infection, and chemotherapy for sufferers. Programmes aimed at the control of leprosy are generally disadvantaged by the negative view most communities have of people who suffer from the disease. This leads to stigmatization of sufferers, and tends to prevent people who develop symptoms from seeking help or treatment, for fear of public contempt.

The case study that follows is not a typical example of a community participation programme in leprosy. Nevertheless, the programme incorporates elements of health education and self-reliance for a specific community, i.e. those affected by leprosy.
Self-care groups for the treatment of leprosy in Ethiopia*

In 1995, leprosy workers in Ethiopia were concerned by the dependency of persons affected by leprosy on the services of the Association for Leprosy Education, Rehabilitation and Treatment (ALERT), which provided hospital and field clinic facilities for leprosy care. Traditional approaches to disease prevention and management, such as education and demonstrations of methods to treat wounds, were receiving a poor response. Instead, persons affected by leprosy increasingly relied on leprosy workers to dress their wounds. This put a strain on the limited financial resources available to ALERT.

ALERT’s response was to organize self-care groups on the premise that “wound healing is the responsibility of those directly affected.” It used the group dynamics of encouragement and accountability of leprosy sufferers to support one another in wound management and obtaining wound dressing materials. Trials were conducted in 1995, and by 1999 there were 72 self-help groups. Six staff members established guidelines, and group facilitators were appointed by ALERT. Group membership was voluntary, and wound dressing materials were provided by the group members. Members were required to participate in problem-solving discussions, develop practical solutions for wound healing and prevention, and monitor each other’s progress. Canvas shoes with microcellular rubber soles were available at subsidized rates at group meetings. Interestingly, there were no handouts in the programme, not food, nor clothing, nor monetary gifts. ALERT provided no wound-healing materials, and group members who presented to local hospitals or clinics were required to provide sufficient reason for their attendance – otherwise they were given advice on wound care and sent away.

Meetings were conducted with group members seated in a circle, and generally followed a format of introductions, news updates, and general conversations about weather, harvest, cattle, and family, etc. Then each member’s appearance and hygiene were discussed. Where improvement was deemed necessary, suggestions were made as to how this could be achieved. Group members examined each other’s hands and feet for skin condition and wound status, offering questions and comments on appropriate care for each person. The group leader or visiting facilitator ensured advice was appropriate to the particular condition. During the first six months, the facilitator monitored progress of the group, and recorded the solutions it decided upon.

Throughout the course of the programme, the self-care groups utilized a number of materials for care of wounds that, prior to the programme, many had been reluctant to use. Follow-up assessments were conducted at 6 and 12 months. All groups showed a reduction in number of members with one or more foot wounds. A dramatic reduction in wounds after the first six months of the programme occurred, which was subsequently sustained. Unintended outcomes of the programme were groups members’ feelings of “belonging to a group”, improved self-respect, and confidence to participate socially. Group members also assisted each other if a person required help with harvesting and house repairs – occasionally, group members’ families also gave assistance. Some groups spontaneously began work on more general environmental hygiene, such as building pit latrines and attending to the cleanliness of home compounds.

Costs associated with the programme were essentially those pertaining to salary, travel, and accommodation for the leprosy workers who acted as facilitators to the groups, at approximately US$ 20 per visit to each group. Anecdotal evidence also suggested that health service utilization was reduced after the introduction of leprosy self-care groups.

*from Benbow and Tamiru, 2001
5.7 Malaria

Effective malaria control is dependent on knowledge of local epidemiology, availability of effective technology, health services structure, logistic and financial capabilities, and national commitment (Anon, 1983; Shiff, 2002). Environmental interventions to reduce breeding sites, and vector control, were important factors in the decline of malaria throughout much of the 20th century. However, vector resistance to DDT, problems in financing and sustaining residual-spraying programmes, parasite resistance to antimalarials, and the migration of people to and from endemic areas hampered malaria eradication and control efforts. Decentralization of health services was advocated to improve services for the rural poor (Shiff, 2002) and empower local governments (Espino, 1999); however, there was resistance to this approach in countries such as Ethiopia (Gish, 1992) and The Philippines (Espino, 1999).

Personal protection measures, such as bednets and treatment, are most compatible with a primary health care structure (Gish, 1992), and vector control measures are considered particularly suitable for community participation. In Africa, measures aimed at reducing human-vector contact are the “best established” methods of control (Eisele et al., 2000). Bednets have been particularly effective for preventing malaria (Richards et al., 1993; Kroeger et al., 1995; Rowland et al., 1997) despite difficulty in sustaining community bednet use over time. Sustained bednet use is often compromised when malaria incidence decreases or cost recovery schemes are discontinued (Makemba et al., 1995; Lengeler and Snow, 1996; Rowland et al., 1997). Residual house-spraying was unacceptable to residents, particularly where household members did not understand the reasons for house-spraying (Vundule and Mharakurwa, 1992) or possessed alternate understandings of the aetiology of the disease (Espino and Manderson, 1997).

The emergence of rapid diagnostic tests during the last decade has opened a whole new approach to community-based programme management (Cunha et al., 2001). Treatment nearest to where transmission occurs, or as soon as illness is recognized (at home or in the community), tends to be more acceptable to communities than treatment at rural clinics (Bell et al., 2001). Moreover, diagnosis and treatment is often more cost-effective when it occurs in the community (Pang and Piovesan-Alves, 2001).

Despite the argument for vector control, we present two cases of community initiative that utilized community organization, community health education and health workers for mass drug administration and malaria treatment.

Mass drug administration and health education campaign in Nicaragua*

Garfield and Vermund (1986) describe the dramatic, countrywide mass administration of the drug chloroquine in Nicaragua, that occurred after the Somoza administration was overthrown in 1979. Under the Sandinista government, the Ministry of Health took advantage of a nationwide literacy campaign to promote malaria control, through “mass organizations” comprised of community residents, or people with similar backgrounds. Some of these organizations were legally constituted groups prior to 1979 (including a women’s organization, AMLAE), and others had been clandestine groups during the war. In addition to these, labour, church, and governmental groups also participated in the campaign (including teachers, health workers, office workers, and farmers).

The country’s successes with the nationwide polio vaccination and *Aedes aegypti* source reduction campaigns inspired a plan to administer chloroquine to every Nicaraguan person aged one year and older. A health education division was created in the Ministry of Health and 11,000 volunteers were trained as auxiliaries. Fifty-five thousand volunteers were trained to take a population census, administer the drugs and fill in the Ministry of Health report forms. Through a multiplier effect, more than 73,000 volunteers were trained from a seed of 40 health educators. In addition, the popular media was put to full use. Garfield and Vermund (1986) claimed that the campaign prevented 9,200 new malaria cases. The spill-over benefits of the massive health education campaign and mobilization were participation in other health programmes (e.g. immunization), community empowerment,
5.8 Onchocerciasis

Onchocerciasis is one of the leading causes of blindness and visual impairment in disease endemic developing countries of tropical Africa, Latin America, and the Arabian Peninsula. Infection is caused by a filarial parasite, *Onchocerca volvulus*, which is transmitted by blackflies (*Simulium spp*). The adult worms live in fibrous nodules under the skin and in connective and muscular tissues. Female worms produce numerous microfilariae, which migrate from the nodules to the eyes, skin, and other organs, and produce most of the symptoms associated with infection (World Health Organization, 1995).
The Onchocerciasis Control Programme (OCP) in West Africa, a collaboration of national and international donor and sponsoring agencies, has reduced disease incidence, prevalence and complications (ophthalmological and dermatological) in countries originally involved in the programme – Côte d’Ivoire, Benin, Ghana, Mali, Niger, Togo, Burkina Faso.

Until the late 1980s, vector control through larvicide was the main control strategy (World Health Organization, 1995; Benton, 1998). Since OCP became operational, the economic benefit to participating countries has been substantial, primarily through reduced incidence of the disease (World Health Organization, 1995; Benton, 1998). Recently, the control programmes have been devolved to participating countries, and have, with state assistance, proved sustainable in the short term. However, donation of the microfilaricide ivermectin for global use by Merck and Co. Inc. spurred large-scale drug distribution programmes in endemic countries, and large-scale ivermectin treatment has since become an important component of onchocerciasis control strategies (World Health Organization, 1995). Because of low coverage rates, among other problems, the distribution of drugs through rural clinics has a minimal effect on transmission of the disease (Amazigo et al., 1998).

For interruption of transmission in high-risk areas to be effective, ivermectin must be administered annually for at least ten years (World Health Organization, 1995; Hewlett et al., 1996). Long-term sustainability of large-scale distribution of ivermectin and/or larvicide is necessary because of the risk that reinvasion by the vector in onchocerciasis-free areas may occur. However, the outlook is optimistic for self-sustaining, community-directed treatment with ivermectin through community-based distributors (Amazigo et al., 1998). This is particularly the case in participant countries of the African Programme for Onchocerciasis Control (APOC), where onchocerciasis is still considered a public health problem (Remme, 1995; Hougard and Sékétéli, 1998). However, the challenges remain to be the following: integrating the strategy into primary health care and other administrative structures; sustaining local financial contribution; and maintaining two-way processes of communication between community, field personnel, local managers and policy-makers (Amazigo et al. (2002). Community participation cannot replace the multi-national, vertical, long-term, insecticide treatment of rivers in West Africa to control onchocerciasis (Service, 1993), but it is an important component of community-directed treatment of onchocerciasis. With regard to the distribution of ivermectin, community participation is advantageous because delivery costs are potentially reduced (Amazigo et al., 1998). Following the apparent success of onchocerciasis programmes in Africa, there is optimism that elimination programmes in the Americas will have similar success (through the Onchocerciasis Elimination Programme for the Americas), with ivermectin treatment delivered to the population every six months, multi-agency cooperation, and political and infrastructural support in each participating country (Blanks et al., 1998).

Outside APOC, there have been a number of other community programmes for the control of onchocerciasis. In Uganda, a community-directed/community-based treatment programme with ivermectin has been established (Mutabazi and Duke, 1998; Okwero, 1998). In Nigeria, a system of compensation for community expenses through internal and external support (Richards et al., 1996) has transformed the programme-designed and programme-directed distribution of Mectizan into a programme of community-directed treatment (Jiya, 1998; Miri, 1998). Cost-recovery schemes for ivermectin distribution have also been introduced in Cameroon and Chad (Godin, 1998).

**Onchocerciasis control in Plateau State, Nigeria**

In Plateau State, Nigeria, the Plateau State Programme was introduced for the control of onchocerciasis. It coordinated state, local and community teams towards the objective of providing Mectizan (ivermectin) to 80% of all individuals living in communities where onchocerciasis was endemic. The programme was initiated under the River Blindness Foundation in 1991, in collaboration with the Ministry of Health. The international distribution of Mectizan was governed by guidelines established by the Mectizan Expert Committee (MEC), which required certain basic
administrative activities to be carried out during distribution of the drug to targeted communities. Annual reports were required by the MEC before programmes were re-supplied with new drug shipments, including information on number of persons and communities treated, adverse effects, and tallies of tablets remaining after the implementation of annual programmes.

The Plateau State Programme incorporated three levels of staff for the distribution of Mectizan - a state onchocerciasis control team (SOCT), a local government control team (LOCT), and community-based distributors (CBDs). SOCT and LOCT staff were responsible for training CBDs, who were in turn responsible for the distribution of Mectizan to 500-1000 members of their respective communities. Initially, in 1992, two mobile teams travelled from village to village to distribute ivermectin, but this method of distribution was found to be logistically unworkable, so CBDs were employed thereafter to control and distribute ivermectin.

The recruitment of appropriate CBDs was often problematic for programme organizers. Initially, it was thought that village health workers and traditional birth attendants would be the most appropriate persons to distribute the drug, but many of these people were illiterate, so they were unable to fulfill the administrative requirements of the MEC. Subsequently, communities were encouraged to nominate CBDs who were able to speak local dialects, read, write, and perform basic arithmetic. Local Government Areas (LGAs) paid CBDs during the first year of the programme, but this proved problematic – some LGAs did not pay their CBDs, logistical problems meant that CBD wages were often siphoned off before they reached the people for whom they were intended, and the desirability for currency-reimbursed employment meant that “financial, political, and familial considerations caused by the payment of wages... often resulted in the selection of a CBD who was not the best qualified person”. Consequently, communities targeted for treatment were encouraged to assume responsibility for CBD reimbursement. Some 10% of community leaders were unwilling to pay the CBD, so these communities dropped out of the programme.

The programme was perceived as highly desirable by local government officials, which meant that although 1248 communities were assessed as endemic by LOCTs, when the SOCT did follow-up surveys, only 60% of villages originally recorded as endemic were in need of Mectizan distribution activities. Moreover, knowledge, attitudes and practice (KAP) studies were conducted in 15 communities prior to implementation of the programme, and “given the great variety of cultures in Plateau state, the health-education and mobilization messages that were devised on the basis of these surveys were not appropriate or adequate in every community”. Subsequently, LOCTs and SOCTs conducted special re-education campaigns, targeted toward specific communities, which substantially increased acceptance and coverage in each community. Distribution of Mectizan also had to take account of the particular cultural and religious characteristics of specific communities, particularly regarding the timing of drug distribution. Sustainability of the programme was adversely affected by the high turnover of local politicians. This meant that Plateau State Programme staff frequently had to return to LGAs and re-advocate the benefits of programme participation. Moreover, continued community support for the CBD tended to reduce once the signs and symptoms of onchocerciasis began to diminish. Both circumstances meant ongoing and active participation by programme staff.

In the first three years of implementation (1992-1994), all potentially endemic communities were assessed. More than 3000 rural villages were selected as eligible for treatment and more than 1500 staff at all levels were trained. By 1996 moreover, 564 731 individuals in 980 endemic communities were receiving annual treatment, representing 87% of treatment objectives for the “at-risk” population. Sentinel studies of ten communities indicated that skin-snip positivity in adults aged greater than 20 years dropped from 63% in 1992 to 26.4% in 1996, and microfilarial densities from a mean of 3.08 microfilariae/snip in 1992 to 0.33 microfilariae/snip in 1996.

*from Richards et al., 1996; Miri, 1998
5.9 Schistosomiasis

The natural history of schistosomiasis is complex. The period of incubation is long, the symptoms are chronic, and the signs and symptoms associated with each species of schistosome are variable. Furthermore, the pathology associated with chronic infection is debilitating. Schistosomiasis is endemic in areas where sanitation is poor and the snail vector present. As a consequence, it is typically accompanied by a variety of other health problems.

Effective control programmes must incorporate environmental control and behavioural change due to the complex life cycle of the parasite. Human reservoirs are not necessary for continued transmission of the parasite; transmission can be maintained by mammalian reservoirs such as the water buffalo and dog. For all forms of schistosomiasis, necessary components of effective control include the provision of domestic contaminant-free water supplies, adequate sanitation, snail elimination, chemotherapy for infected persons, and a reduction in incidence of unnecessary contact with contaminated water (Yu et al., 2001). Vector control measures are financially, ecologically, and operationally impossible in most developing countries. The long life span of adult schistosomes in adult hosts necessitates snail control programmes to be sustained for decades. Improved sanitation is considered more effective towards limiting schistosome transmission than reducing general contact with infected water. Antischistosomal drugs are considered an effective means of reducing infection-related morbidity but not necessarily for controlling disease transmission.

*S. haematobium* is the most amenable of the four species of schistosome to community interventions. The diagnosis can be made with relative ease by urine examination using reagent strips that detect blood in the urine. Diagnosis of infection with other species of schistosome is more difficult. For *S. mansoni* and *S. japonicum*, examination of stool samples by microscopy is required. Control of schistosomiasis is complicated because human contact with contaminated water is an unavoidable occurrence in all places where the disease is endemic, even where sanitation and potable and domestic water supplies are accessible to most people. As a consequence, effective disease control necessitates behavioural change. This is often difficult or impractical when people rely on water sources for economic and/or subsistence production. In this context, consultation and cooperation through community participation is a crucial aspect of disease control. For projects to be effective and sustainable, communities need to be involved from initiation. Projects must be built on an understanding of local social, cultural, economic and political factors (Huang and Manderson, 1992) and on disease priority in relation to other community concerns (Tanner et al., 1986).

**A community-based approach to *S. haematobium* control in Kaele, Cameroon**

The Ministry of Public Health of Cameroon, through its primary health care (PHC) programme, initiated a schistosomiasis control programme in 1991 after inadequacies in communication between the community and health services were identified as a major deficiency in previous initiatives for schistosomiasis control. Kaele, in the extreme North Province of Cameroon, suffered hyperendemic levels of urinary schistosomiasis (*S. haematobium*), and locally the infection was considered to be one of the most important endemic diseases. This facilitated the introduction of community control measures in the district.

By 1990, Kaele had been identified as an appropriate site in which to develop a practical and cost-effective model for schistosomiasis prevention. Some of the reasons that contributed to a preference for *S. haematobium* as the target for intervention (the other schistosome species endemic to the area was *S. mansoni*) were: 1) identification and diagnosis of infection is accomplished with comparative ease; 2) the symptomological association of *S. haematobium* with disease of the genitalia and reproductive tract meant that it was easier to capture people’s attention in relation to this disease, and consequently to facilitate appropriate diagnosis and treatment-seeking behaviour; 3) schistosomiasis was perceived by local people as a disease that required treatment. Therefore, effective treatment of the malady by a PHC-initiated project would increase people’s confidence in the organization and facilitate initiation of future PHC projects in the area.
5.10 Tuberculosis

As in the case of malaria, the Alma Ata Declaration provided the impetus for integration of vertical tuberculosis control programmes and hospital-based tuberculosis services with primary health care programmes. It has been recognized that community participation in tuberculosis control programmes suffers from insufficient facilities for supervised treatment by health workers, underdeveloped resources available to voluntary organizations, and the burden on participation by people suffering from the disease (Chaulet, 1984; Holm, 1984). Private health providers remain a favourite choice for individuals with symptoms of tuberculosis (Auer et al., 2000; Tupasi et al., 2000). The need to bring the private health sector into national control programmes is emphasized by Uplekar et al. (Uplekar et al., 2001).

The incidence of morbidity and mortality associated with tuberculosis has increased over the last decade with the emergence of multiple-drug resistant strains of Mycobacterium tuberculosis (MTB) and an increased incidence of HIV/AIDS (Rattan et al., 1998). Tuberculosis treatment is adversely affected by widespread delay in treatment, poor compliance of patients to treatment regimes, and the practice of “shopping” for treatment (Auer et al., 2000; Uplekar et al., 2001). These problems are compounded by inappropriate patient management. Rivera et al. (1999) observed more drug-resistant M. tuberculosis strains among patients who had previous anti-tuberculosis treatment compared with
to those with no treatment at all. Two-thirds of those infected with *M. tuberculosis* have a chronic productive cough, and they will seek help “if it is available” (Holm, 1984). However, Tupasi et al. (2000) report that, in the Philippines, people with symptoms of pulmonary tuberculosis or who have bacillary disease (i.e. a positive sputum smear) either do nothing about their symptoms or use self-treatment. The problem of multidrug resistant MTB may be partially redressed by directly observed treatment short-course medication (DOTS) (Yew, 1999). Second-line and third-line anti-TB drugs are available, but these may only be obtained at high cost, have more side effects, are less effective, and their use must be strictly monitored (Crofton et al., 1997). The challenge remains to enable patients’ involvement and interest in the management of their disease.
6 KNOWLEDGE GAPS

Community participation was presented as both a means to, and an objective of, health development projects and community-based research. While exploring the role of communities in reducing the incidence of disease, researchers have considered appropriate preconditions for community participation, and the community characteristics that facilitate or discourage people's participation. However, social research concerned with participation has, to date, focused on programme operations. Do communities perceive that their needs have been met? There remains a need to explore the social and political structures in which tropical disease control programmes operate. There is also a need to identify strategies that have the greatest impact on disease transmission, that are acceptable to the people they affect, and that can be integrated into their daily lives and community structures. Control issues in vector-borne and tropical diseases have to be understood from the social, political, economic and cultural contexts of the communities involved (Midgley, 1986; Oakley, 1991).

We have noted that people involved in the development of disease control strategies and health policies (such as health project personnel and social scientists) have viewed culture in contradictory ways, principally, as a set of “beliefs” and “customs” that were “obstacles” to new ideas (Stone, 1992) rather than as a parallel and legitimate system of diagnostic categories, syndromes, and treatments with their own pathways to, and strategies for, securing care. Research conducted following the Alma Ata Declaration focused on how communities might participate in disease control programmes and on practical aspects of participation in primary health care strategies (i.e. as facilitatory communities). While successful programmes acknowledged the role of structural and political factors in community participation programmes (Stone, 1992), in most cases the operational focus was on the effect of culture on the effectiveness of programmes. Failures were reluctantly reported (Botes and Van Rensburg, 2000).

6.1 Fluidity of community participation

In some respects, the definition of community participation, although profound, is misleading. Within marginalized communities, individuals differ in their ability to participate (Botchway 2001), and equality is achieved or forced by very subtle coercion. As we have already argued, the different ways in which community participation is understood ranges from the practical to the idealistic. We have also drawn attention to deficiencies in the way “communities” have been conceptualized in community participation programmes – namely, as discrete from external agencies that provide the impetus for tropical disease control measures. Because the “new” communities formed in these processes are properly comprised of both the “original” community and the external agency, sustained control of infectious diseases must necessarily involve continued participation by ministries of health and local health programmes and agencies. In this respect, the idealistic notion of community participation whereby members of coherent groups identify, prioritize and resolve their own problems, is neither feasible nor appropriate. Most of the diseases with which we are concerned are especially prevalent in poor communities. Systems and strategies are required that are relevant to tropical disease control; are sensitive to individual or group differences; address inequalities that occur, both within and between these populations and service providers; and promote collaboration between them. We also reiterate the need to promote opportunities for community participation: education, information and communication, supervision, training, essential supplies, efficient referral systems (World Health Organization, 1988), and political support. Hence, we have asked, given the constraints that disease control places on community participation, should concepts and ideals be redefined?

The definition of community participation as empowering is also paradoxical. Governments are willing to support community participation, but not at the cost that their authority is undermined (Gilbert and Ward, 1984; Midgley, 1986). There is disagreement regarding the notion that true participation is achieved only when the community is in full control of the process or decides entirely by itself (White, 1982). The ideals of community participation appear to work best in democratic
societies or in environments that promote democratic participation; however, this may be a function of the increased resources and structures often found in democratic societies. Although community participation is often advocated as a democratic form of social participation, on close examination this is not obviously the case. Community participation contains a strong ethic of egalitarianism, and often emphasizes public good over individual autonomy, which may conflict with the association of democratic process and individualism. The relationship between forms of political representation and community participation has not been adequately scrutinized.

6.2 Strategies and schemes

We still lack a good understanding of community response and behaviour when presented with a disease control strategy or scheme with which community members are expected to comply. Control programme managers routinely take an interventionist approach, and both governments and donors tend to construct programmes with a focus on issues of process, activity and outcome. Alternately, ideals of optimal community involvement emphasize the need for health providers and health programme recipients to “listen to the people” either prior to, or during, programme development (Tanner et al., 1986). Listening well to analyse social, cultural and environmental factors affecting disease transmission requires substantial effort (Barbosa and Barbosa, 1998). This approach is rarely adopted in tropical disease control strategies. Typically, programme managers identify effective control measures first, and then explore community participation issues. Vector-borne and tropical disease control must adopt strategies that community members understand, and that are implemented through structures they respect, are familiar with, and to which they have access.

As in other health care programmes, community participation involves a spectrum of activities and processes: organizing, contributing, planning, evaluating, and cooperating (Ahmed, 1978; Woelk, 1992). These may occur simultaneously or sequentially and not in the particular order listed. To get these principles across to control programme managers, and enable them to put the principles into practice and sustain the practices, requires multilateral involvement and foresight. The farming community in Sicuani of the Cuzco region of Peru illustrates socio-psychological structure that enabled compliance to treatment for mucocutaneous leishmaniasis and prescience by local government institutions. Community directed treatment for lymphatic filariasis in India, and the distribution of Mectizan by community-based distributors in Nigeria, highlight the unsuitability of these approaches in existing social, cultural and political situations of the countries. The approaches contrast with the use of existing knowledge and practices related to schistosomiasis to the advantage of the control programme in Cameroon. Providing equipment designed for communities to trap tsetse flies, and bicycles to collect the traps in the Sudan, and state subsidies for improved housing to control Chagas’ disease in Venezuela and Bolivia, illustrate enabling strategies for communities to participate in disease control measures. In general, it is unlikely that there could be mass support for disease prevention or control, particularly for endemic diseases. Massive community mobilization for mass drug administration has tended only to occur in specific social and political circumstances; in Nicaragua (Garfield and Vermund, 1986), it was a reaction to decades of oppressive rule by the Somoza regime. A similar phenomenon, although not health related, was observed in The Philippines in 1986, when Ferdinand Marcos was ousted from office. Since then, mass mobilization has been used in national immunization day campaigns, but not for routine health programmes.

Traditional practices

An issue that could be addressed more thoroughly is the extent to which community participation can be maximized by the integration of health services and control strategies with traditional or indigenous practices. During the agricultural cycle in rural South-east Asia (such as in Indonesia, Malaysia and The Philippines), systems operate to ensure cooperation during the rice harvests, when people pool labour to harvest each field as it ripens (gotong royong or “working together” in Malaysia, and bayanihan in The Philippines), or contribute labour, food or cash to support families at times of marriage and
death. Rotating credit funds and funeral funds are not uncommon. Generally, the potential utility of such arrangements to community participation initiatives has not been acknowledged by external agencies in the control of infectious and vector-borne diseases. Routinely, the assumption is that attitudes and behaviours need to be changed, and so potential roles for local social relationships and values in control programmes are not considered; hence, there has been little consideration of how disease control strategies might adapt to or be integrated into community ways of life. Moreover, control programmes have assumed that community structure and infrastructure are fixed. Consequently, alternative strategies to shift the patterns of disease and community structure have not been considered.

Community groups

Community health organizations and health workers are mechanisms through which community participation is generated and expressed (Woelk, 1992). Through community health workers and middle-level programme managers, leadership is handed to others, who are often newly arrived in the community (Patrick and Wickizer, 1995). Community participation programmes have occasionally secured the assistance of existing community committees to help with health initiatives. These committees often take on responsibility for working toward collective goals by utilizing available resources and motivating other villagers. Oftentimes, these committees are able to secure cooperation, resources and networks within the community, which may greatly facilitate the speed at which health programmes are introduced. In practice, the distinction between community health workers and committees is not always clearly demarcated, and they sometimes share roles. Both health workers and committees have a similar objective in the context of community participation programmes – their goal is to transform their respective communities from passive recipients into active participants of health care programmes. Of course, as already stated, the degree of active participation in particular initiatives is variable, and depends on the role afforded the community in the development of the health programme. Participation in vector-borne disease control activities is time consuming, and often only a few people within a community are able to undertake health provider roles. In some cases, seasonal work requirements compete with health care provider roles. Initial interest in volunteer work activities is occasionally induced by a belief that paid work may follow, and when it does not, there may be high attrition.

Community organizations that promote effective community participation are often difficult to develop. The balance of power between community health workers and clinic staff who supervise them may be labile and this may produce tension. The value of community health workers, and the relationship between community health workers and clinic staff needs to be scrutinized closely. Health workers are clearly critical in meeting the medical and public health needs of communities. Some commentators have suggested that community volunteers should be employed as a permanent approach to health care (Walt et al., 1989). This is particularly so in poor settings where the ratio of clinic staff to population is low and community health workers provide essential supplementary support.

Health education

One of the benefits of advanced communication technology has been increased community access to health information, and increased familiarity with, and expectations of, the health care delivery system. Even so, the interval between health education and health change may be considerable. Guldan (1996) suggests that with the use of community development methods, behaviour changes from intensive community health promotion (i.e. education) are demonstrated after five years. Yet it is unclear what factors are necessary to facilitate changes in practice, as usually those whose participation is required most are outside the reaches of conventional health education campaigns (media and formal education). Moreover, conflicts remain between community and biomedical models of diseases. A problem facing programme managers concerns how commitment and community interest can be sustained when there is a lack of concordance in understanding the etiology of disease.
Health education remains important as a component of community participation in health programmes and as a precursor to behavioural change. However, knowledge alone is not the determining factor of behavioural change. The form of education may differ according to the specific aims of the programme, and the particular characteristics of the locality, the disease, and the media through which health education is disseminated.

Conventional forms of health education (Lloyd et al., 1994) (i.e. messages “from the top”) are often distorted or misinterpreted as they reach target populations. The following have been proposed: (a) day-to-day experiences with the illness have to be known; (b) the relationship of the vector with disease transmission explained in simple and comprehensive manner; and (c) health education materials developed together with the community (Lloyd et al., 1994) (see also the case of schistosomiasis control in the Cameroon).

**Processes**

We have already noted that in the Alma Ata Declaration, and in subsequent projects, communities are often represented as homogeneous. It is assumed that, through common and coherent purpose, some members of a given community will be able to speak on behalf of, and therefore represent, others. They will be able to motivate others in the community to work towards shared goals. Arguably, this has rarely been the case. As a result of increased migration and integration of community members in cash economies, increasing diversity and inequality in communities at risk of infectious disease has complicated such conceptualizations. In this context, members of disadvantaged and marginalized subgroups are likely not to participate in community participation programmes, and therefore remain beyond the reach of primary health care.

Understanding the association between community and health can improve the design and evaluation of community interventions. Community needs must be established; not all communities regard vector-borne diseases as a health problem. If they are a priority, control programme management should work with the community to develop solutions. The conditions under which this can be achieved should be established, along with the most appropriate people to implement programme objectives (such as community representatives), and the extent to which interventions should be incorporated into existing structures (see the case of onchocerciasis control in Plateau State, Nigeria).

There is also need for increased work on operational aspects of community participation in the context of control programmes (Zakus and Lysack, 1998). Despite attention in the literature to the importance of community in identifying needs as a precondition of participation, there has been some acknowledgement of the difficulties in matching community needs to national (or other) disease control targets, and, at times, the incompatibility of community needs with the control of specific diseases (see the case of filariasis control in Tamil Nadu, India).

Concurrent with these developments, changes in government, including health sector reform, have placed increasing emphasis on decentralization. It is unclear whether decentralization is necessary for community participation, or whether community involvement in identifying local needs will flow on to initiatives for the control of vector-borne diseases. Given the limited resources available at local level, the extent to which other needs – community and administrative – are addressed becomes problematic. Furthermore, the demands of disease control (such as appropriate drug use and compliance to treatment to control drug resistance, and bednet use to prevent malaria) may not be regarded by communities as important; nevertheless, they bear directly on community health.

**Targets: end-users or providers**

Research on vector-borne diseases typically defines the community as the target population for control strategies. The “community” is usually defined as the population at risk in a geographical area. Consequently, definition of the “community” takes account of disease-specific considerations, such as the area where transmission occurs, the individuals at risk of acquiring the disease, vector species habitat
and behaviour in these areas, and human ecology. This may or may not coincide with groups of people who regard themselves as members of a community. Defining the target group for a specific intervention, and characterizing it in a flexible but efficient manner, is, therefore, a major challenge to programme designers. However, it is a necessary step where the distribution of disease is confined and where mass intervention makes little sense.

As already noted, population movement, including urbanization, also makes the task of defining a specific “community” problematic. In urban areas, for instance, communities rarely correspond to geographic location; rather, within a locale there may be a number of communities exposed to infection, but without a sense of purpose that would facilitate participation. “Geographical” or “vector” communities may encompass marginalized, migrant and established populations, poor and wealthy people, and ethnic diversity. Community subgroups often lack the capacity and/or interest to work across communal and socioeconomic boundaries around a particular disease, and indeed, dominant and/or influential groups within communities may also be unwilling to cooperate with other groups. Little attention has been paid to the possibility that people may not perceive themselves as a community, or may not participate in everyday (or occasional) activities as a defined group. Where economic, ethnic, religious or other boundaries are less marked, community participation has greater potential for success (Bermejo and Bekui, 1993). Alternately, stark differences and/or antagonism between community subgroups may render community participation strategies unworkable. It is crucial, therefore, that prospective programmes have knowledge of intra-community group dynamics prior to programme design and implementation.

From case studies of community participation in Central and South America, the following were considered main contributing factors to the success or failure of community participation initiatives: common need for basic services, history of community action, and existence of a local organized structure through which action can occur (Pan American Health Organization, 1984). Moreover, communities with relatively high levels of education, compactness, adequate communication and transportation facilities, dynamic leadership, and which were aware of their rights and responsibilities, were more likely to participate in disease control programmes than communities cleaved by social, economic and political divisions.

Community participation research has focused on communities that are the subject of interventions and/or members of vulnerable communities, but not those who implement and may need to sustain the interventions, or who are responsible for disease control. We know little about the relationship between health service professionals and target communities; quality of care literature is largely concerned with reproductive health. Questions that need to be addressed in this context include: what are the expectations and needs of users of health services? Are they confident with the providers in the system? To what extent does quality of care influence people’s willingness to adhere to behaviours designed to reduce transmission of infection?

Evaluation

Public health personnel often initiate community level interventions without a theory of community change, and prolong interventions without a thorough understanding of their effectiveness (Patrick and Wickizer, 1995). For this reason, increased focus on processes of evaluation is desirable. Evaluation must take account of both the epidemiology and social context of specific diseases. For example, in dengue control, evaluation must accommodate community involvement, and combine these findings with environment and mosquito surveys regarding water storage and potential breeding sites (Gubler and Clark, 1994).

Evaluation procedures should identify needs and systems of intervention, and thereafter examine the effectiveness of programme processes. Above all, the objectives of a given intervention should be clear, and include explicit acknowledgement of the community’s (and its members’) roles, programme expectations, and capacity for sustainability. Sustainability, in particular, is often inadequately evaluated.
There is insufficient regard to how structures and processes of participation are maintained after withdrawal of the external agency. As we have argued, it is likely that the complete disengagement of external agencies from community participation programmes is unfeasible. Continued participation by all members of the “new” community (including the external agency) is probably required for sustainability.

How, and from what and whose perspective are outcomes of community participation in disease control measured? The effectiveness of community participation in tropical disease programmes is often indirectly measured, and increased documentation of the implementation process is required. Moreover, the task of collecting valid baseline data and follow-up data for evaluation of disease epidemiology (such as reduction of mortality) is often the responsibility of primary health care workers, and this role is frequently fraught with difficulties (Anon, 1983; Lengeler et al., 1995).

Prior to intervention, the goals of community participation in particular interventions must be adequately defined. The role of community participation, as a programme component (a means) or an outcome (an end) of the intervention, is a crucial component of effective evaluation. In community controlled programmes, accountability and responsibility for various aspects of intervention must be clearly defined. Moreover, the effects of programme interventions must be reliably measured (Rajagopalan and Panicker, 1984; Richards et al., 1996; Rowland et al., 1997).

6.3 Sustainability and the role of the external agency

As already discussed, strategies for community participation and involvement in health care (i.e. disease control) are often dependent on project managers and/or external agencies, and do not emanate from within communities. Social, political and economic differences, and the presence of various non-government agencies within specific countries, affect the character of community participation in specific vector control programmes (World Health Organization, 1983), as do epidemiological, entomological, ecological, and social conditions. Donor agency staff and control programme managers who are output, rather than process, oriented may inadvertently discourage community involvement in health care and primary health care processes (Botes and Van Rensburg, 2000).

Sustainability is often problematic because donors are reluctant to fund running costs (i.e. in the form of ongoing grants or research projects). Consolidation and institutionalization of research and project strategies do not occur where programme resources are inadequate. Control programme personnel need to make a conscious effort to produce sustainable programmes. Better information on the relational dynamics between project/research team and local participants, be they community or health personnel, is also required (see also Kelly and Vlaenderen, 1996). The nature of these relationships is crucial to the initial and ongoing success of any initiative, yet they are rarely addressed in a substantial way. Mills (1983), in an historical perspective of externally driven control strategies (such as eradication/elimination campaigns), noted the importance of general health services for sustaining results. However, the provision of such health services is often problematic in poor and developing countries (and communities), where resources are often limited and logistical requirements prohibitive. The capacity of communities to obtain sustainable benefit from interventions in such circumstances needs to be addressed more completely.

External agencies (nongovernment organizations, research projects, donor agencies) are rarely held accountable to sustain strategies or interventions that work. Even with external budgetary and programme support, public health activities face many obstacles. Once strategies are determined (through department of health circulars, for example), the clinic staff trained, and health education posters and leaflets distributed, the targeted community is expected to participate in these strategies. This is despite the fact that local implementing agencies, including community organizations, often lack technical links with central government or other agencies capable of providing appropriate support. Without these links, strategies are often hampered, or fail, for lack of institutional support and expertise.
Little research has been conducted to describe how pre-existing mechanisms, such as community assemblies, associations and committees, can be used to support community participation for disease control (Woelk, 1992). In some cases, indigenous structures of governance may collaborate with other agencies without need for extensive or additional support; in others, structures may need to be modified to take account of specific physical, regulatory and socioeconomic environments (Patrick and Wickizer, 1995). The process by which this occurs (or fails to occur) is worthy of further investigation, and may produce valuable information for the implementation of future campaigns.

**Boundaries of empowerment**

What level or degree of community participation is possible, or sensible, in the control of vector-borne diseases? Some authors maintain that strategies are not correctly described as community participation if they do not involve the community at all levels of programme implementation: conceptualization, development, and evaluation (Guldán, 1996). Whiteford (2000) notes that the social and political environment in which interventions are introduced also has a major impact on people's willingness to participate. Citing experiences in the Dominican Republic and Cuba, she argues that in the determination of their willingness to participate in a given programme, people's general level of well-being is not as important as their confidence in government and future outcomes. An important question to be addressed is the extent to which the desire of administrators, policy-makers and control managers for programme efficiency and accomplishment is commensurate with the advocated ideals of community participation – devolution of power, and involvement in decision-making, planning and implementation.

Within communities, there is often tension between the autonomy of individuals and their rights in relation to the group of which they are part. Community participation strategies rely on coordinated activity by all corporate members, and there is an expectation that individuals who are not inclined to participate should put consideration of the group before their own preference. The notion of empowerment may become problematic in such circumstances, as empowerment of the “community” may simultaneously depend on reduced autonomy of some of its members (Hall, 1992). Often, community participation programmes rely upon, and support, existing community leaders and authorities. Although this is sometimes described as “democratic” participation, little analysis of the effect of these techniques on the autonomy of individuals within communities has been conducted, and there has been little work on the extent to which community participation strategies enhance and/or change relations of influence and power within communities. As all programmes aim toward universal participation in various initiatives, this is an important issue for future consideration.

**Resources and skills required**

Small-scale programmes have demonstrated the possibilities of community based primary health care approaches (Ahmed, 1978). Scaling up successful pilot projects and strategies to regional or national programmes and policies necessitates the transfer of basic principles and approaches – but without intensive monitoring and practical assistance. How this might be effectively implemented has not been resolved. Further, pilot studies have rarely been generated indigenously, and little attention has been paid to feasibility, sustainability, cost and effectiveness of programmes, either over time, or with regard to large-scale implementation.

Operational and logistical aspects of tropical disease control are complex. It is acknowledged that community participation through a primary health care system requires better skills and knowledge than has been the case to date (World Health Organization, 1983). Tropical disease control is effective when strategies for programme delivery are contextual and complete, and when technical information is adequate. Services provided, and roles of participants, must be defined and implemented effectively (Shiff, 2002). In very poor communities (and countries), programme managers must consider whether existing resources and skills should determine priorities.
Programme developers must establish whether local health services, and municipal and provincial health offices, have the time and resources for training staff. Technical skills may have to be updated, particularly management skills and decision-making capacities of community health workers. Although communities often carry out control activities, they are not always responsible for making crucial decisions. Provincial and local health authorities assumed this role (see Zakus and Lysack, 1988). Provincial and local health authorities tend to view community participation as a means to carry out control activities, and thus, community participation is a one-way relationship. Community members, however, will only participate if they perceive a benefit for their participation, and believe their expectations will be met.

Urban versus rural

Community-based services (and community participation, if not involvement, in these services) in rural and urban areas differ with regard to conditions under which Health for All is implemented (World Health Organization, 1988). There have been dramatic changes over recent decades in terms of population mobility and distribution. Increasing landlessness, economic crises and civil strife have led to large numbers of people migrating within their own countries as seasonal labourers and for subsistence living. This has various implications in terms of disease control and health care. The population is often unstable and heterogeneous in areas that attract migrants, making collective effort for disease control difficult to implement. In urban centres, rapid increases in population strain the government health service resources and place pressure on the environment, and increase the opportunities for proliferation of vectors of infection.

The responsibility of municipal government (including decision-makers and programme planners) to mobilize state and community resources for vector control has been noted (Knudsen and Sloof, 1992). Government in urban areas tends to be more visible due to the presence of media organizations (newspapers, television, radio), but health and education services, although present, are often not easily accessible. In rural areas, specifically for people living in remote villages, government structures are less noticeable and health and education services are not accessible. Nevertheless, health and public education services are more visible than other national services regardless of locale. Unfortunately, governments allocate limited funds to these services and personnel are poorly paid; thus, their potential effectiveness is limited.

Among urban and rural poor, structures to enable the community to participate in vector-borne and tropical disease control are often absent. In addition, social support to facilitate community participation is lacking. Without external assistance, some marginalized communities lack cohesive organization and possess limited means to articulate their needs. As a result, the feasibility of community participation is compromised particularly where the ideal of community “empowerment” is desired. Programme conditions must often be imposed externally where it is difficult to involve communities in conceptualizing, planning and implementing programmes.

6.4 The role of state and political and health sector reforms

Comprehensive and integrated primary health care is neither cheap nor easy, particularly given the inherent countertendencies of vertical structures and programmes. This has been a particular problem with tropical disease, where there has been considerable resistance to integration from vertical programmes. Primary health care programmes appeared to be most successful in socialist countries where political will was strongest. However, Stone (1992) points out that the degree of genuine community participation in some of these programmes is questionable (compare Rifkin, 1983). This was certainly the case in China with respect to schistosomiasis control. Mass mobilization for snail eradication was possible and acceptable during Mao’s era but it is neither politically nor logistically possible today (Yuan et al., 2002). As Whiteford (2000) illustrates, centralized states with a strong ideological commitment to community involvement have been relatively successful in sustaining community-based health programmes regardless
Community participation and tropical disease control in resource-poor settings

of the ability of the government to underpin these programmes financially. Government support of participatory approaches has always been emphasized (Bermejo and Bekui, 1993; Tatar, 1996; Botes and Van Rensburg, 2000) but a national political commitment to meet community basic needs is not enough. Sustainable community participation requires that people are involved without coercion, with values of civil society and good governance recognized from within and not externally imposed.

In stable, democratic, political environments, and among middle class or less impoverished communities, people have more control over their lives and are in a better position to participate and articulate their needs. If a clear statement of health problems wins support from the political sector (Guldan, 1996), then these communities have an advantage over less privileged sectors of society. Communities in countries with unstable governments or impoverished conditions often face practical barriers in development and may be reluctant to work with government for diseases control purposes. With devolution and decentralization, political commitment to primary health care is more unstable and uncertain. Local government units are often left to cope with increased responsibilities resulting from health sector reforms (Stone, 1992). As Yuan et al (2002) have illustrated, where health sector reforms include revenue raising as well as budgetary responsibility, general commitment to public health tends to decline. Thus, programme sustainability by these means is often untenable. Conventions of fees-for-service tend to be effective only in curative settings or clinical environments and not in the context of health prevention or promotion.

The emerging role of national control programme managers is to coordinate and determine strategies in countries where health services are decentralized. However, there must be flexibility to allow adaptation to local circumstances (Rifkin, 1986; Bermejo and Bekui, 1993), and local programme managers must have control over financial resources and programme implementation (Midgley, 1986). How this might fit into the socio-cultural and biomedical dynamics of disease transmission requires further consideration, and points to a need for research on governments and their agencies, as well as on communities who are the subjects of tropical disease programmes.

6.5 Global events and advocacies, local consequences

The Alma Ata Declaration reflected recognition that inequalities in health status and services evolve from the specific economic, socio-cultural and political characteristics of countries (and communities). These characteristics are derived historically and are influenced by global relations. However, global inequalities were not addressed at Alma Ata. Nevertheless, people living in marginalized and rural areas need assistance to cope with global changes that affect their lives. Societies and the communities therein are rapidly changing, and in some areas, communities are disintegrating, with a general movement towards individualization (for survival). In this context, labile political structures, economic downturns, and civil strife all impact on individuals’ capacity to control their conditions of living and their health status. A question yet to be adequately addressed concerns the role and place of primary health care in community life, and how it might contribute to the mobilization of communities. Economic recession in several developing countries has affected programmes and activities designed to support and encourage community participation (Woelk, 1992). It resulted in a continued need to develop both communities and those who exercise power over them.

In the new millennium, the significance of political leadership in the global effort to contain infectious and tropical diseases is increasingly being recognized (see also Kekki, 2003). The need for equity in health care provision is also recognized, and must be considered in the context of health sector reform, advances in bio-, medical and information technology, global strategies in fighting infectious and tropical diseases, and an increasing number of novel approaches for control of infectious diseases – rapid diagnostic tests, cost-recovery schemes for community-based strategies and genetically modified vectors. These developments provide ongoing challenges for community-based work and community participation in disease control while creating new research agendas and practical tests for governments, agencies and populations themselves.
CONCLUSION: THE RESILIENCE OF COMMUNITY PARTICIPATION

There are fundamental errors of logic in connecting Health for All, primary health care and community participation. The Alma Ata Declaration appealed to governments, particularly due to its goals of self-reliance, with individual communities less dependent on others to make decisions regarding their health needs. However, this was not straightforward. The dilemma was that while, ideally, initiatives and labour should be determined and provided by communities, communities need guidance to define their needs and identify ways of responding to them. Indeed, the major achievements in disease control over the past decade have occurred with a clear lead from government, and the degree to which communities prioritize health over other needs is uncertain.

Health for All by the Year 2000 was an unrealized dream. Already by the early 1990s, primary health care goals had shifted from a comprehensive approach towards the attainment of equity, and there was increased interest in ethics in health research and patient care (Hall, 1992). Advances in technology tended to benefit developed countries disproportionately, exaggerating the gaps between developed, developing, and least developed countries. Concomitant with this was an increasing sense of pessimism with the feasibility of Health for All. In this context, future challenges for community participation in the control of vector-borne and infectious diseases are daunting. In the late 1990s, global health policy regarded Health for All, at least in part, as a call for social justice. No one will argue with the statement that health is regarded as a human right (Visschedijk and Siméant, 1998), but how this might be effected to reduce the transmission of infectious disease while ensuring equality is problematic.

The control of vector-borne and tropical diseases generally has an altruistic undertone. Use of tsetse fly traps, disposal of potential *Aedes aegypti* breeding (water) containers, and use of insecticide-treated bednets benefit not only those who practice these control measures but the community as well. The challenge for community participation in tropical disease control is to adopt a community development approach and to move beyond health borders. A broader perspective of disease control strategy is needed – one that appreciates the complex ways that economic and political factors interact with the social environment to produce health (see also Patrick and Wickizer, 1995) while remaining focused on who will, and should, ultimately benefit from those strategies. Community participation remains a guiding principle in tropical disease control, but its future success is dependent on sustained and continuous collaboration between external agencies, governments, and communities.
## ABBREVIATIONS

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired immunodeficiency syndrome</td>
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<tr>
<td>ALERT</td>
<td>Association for Leprosy Education, Rehabilitation and Treatment</td>
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<tr>
<td>APOC</td>
<td>African Programme for Onchocerciasis Control</td>
</tr>
<tr>
<td>BCG</td>
<td>Bacille Calmette-Guerin</td>
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<tr>
<td>CARE</td>
<td>Cooperative for Assistance and Relief Everywhere</td>
</tr>
<tr>
<td>CBD</td>
<td>Community-based distributors</td>
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<tr>
<td>CDC</td>
<td>US Community Disease Control and Prevention</td>
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<tr>
<td>ComDT</td>
<td>Community-directed treatment</td>
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<tr>
<td>DEC</td>
<td>Diethylcarbamazine</td>
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<tr>
<td>DDT</td>
<td>Dichlorodiphenyltrichloroethane</td>
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<tr>
<td>DOTS</td>
<td>Directly observed treatment short-course</td>
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<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<td>HST</td>
<td>Health services treatment</td>
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<tr>
<td>KAP</td>
<td>Knowledge, attitudes and practices</td>
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<tr>
<td>LGA</td>
<td>Local government areas</td>
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<td>LOCT</td>
<td>Local onchocerciasis control team</td>
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<tr>
<td>MDT</td>
<td>Multidrug therapy</td>
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<td>MEC</td>
<td>Mectizan expert committee</td>
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<td>MSD</td>
<td>Merck Sharpe and Dome</td>
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<tr>
<td>OCP</td>
<td>Onchocerciasis Control Programme</td>
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<td>OEPA</td>
<td>Onchocerciasis Elimination Programme for the Americas</td>
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<tr>
<td>SOCT</td>
<td>State onchocerciasis control team</td>
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<tr>
<td>UNICEF</td>
<td>United Nations Children’s Fund</td>
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<tr>
<td>VHW</td>
<td>Village health worker</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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