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Using participatory mapping to inform a community-randomized trial of HIV counseling and testing

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Abstract

Participatory mapping and transect walks were used to inform the research and intervention design and to begin building community relations in preparation for Project Accept, a communityrandomized trial sponsored by the U.S. National Institute of Mental Health (NIMH). NIMH Project Accept is being conducted in five sites within four countries including Thailand, Zimbabwe, South Africa and Tanzania. Results from the mapping exercises informed decisions about the research design such as defining community boundaries, and identifying appropriate criteria for matching community pairs for the trial. The mapping also informed intervention related decisions such as where to situate the services. The participatory methods enabled each site to develop an understanding of the communities that could not have been derived from existing data or data collected through standard data collection techniques. Furthermore, the methods lay the foundation for collaborative community research partnerships.

Keywords

participatory research methods; mapping; community-randomized trial; formative research

INTRODUCTION

Community-randomized trials are increasingly being used to evaluate the impact of largescale public health interventions aimed at influencing social determinants of health behavior (Green, 1997; Freedman, Gail, Green & Corle, 1997; Todd, Carpenter, Li, Nakinyingi, Gray & Hayes, 2003). There are a number of challenges associated with designing and implementing a community-randomized trial, however. First, ensuring that intervention and

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control communities do not systematically differ from one another in ways that will influence study outcomes is a key challenge in research design (Smith and Morrow, 1996; Green, 1997). While matching of communities can ensure that clusters receiving the intervention are more likely to resemble those not receiving it in important ways (Freedman, Gail, Green and Corle, 1997), communities should only be matched on factors known to be highly correlated with the outcome of interest. Inappropriate or inadequate matching can reduce the power of the study to detect a real effect when the sample of communities is small.

Second, determining the boundaries of communities to be used as analytical units in community-randomized trials is also a key challenge. Communities are often defined administratively, based on geography and population size. However, these administrative boundaries may not correspond to the community definition of boundaries. Delineation of community boundaries is critical when interventions are designed to operate through community-level change. If community boundaries have been defined in ways that do not accurately reflect patterns of interaction among individuals, the intervention may not have the desired impact at the community level. In addition, if boundaries are not internally consistent with the local use of space, then cross-over between communities randomized to different conditions may become an issue for the trial. This type of cross over represents an important threat to the internal validity of a trial.

Finally, many intervention design issues need to be addressed prior to implementing an intervention trial in a community. Formative research, or research conducted prior to the implementation of a project, is now considered a key step in the intervention development process in that it allows investigators to explore potential barriers and facilitators to intervention adoption, develop appropriate communication strategies to promote adoption of the intervention should be delivered (Gittelsohn, Harris, Whitehead, Wolever, Hanley and Barnie, 1995; Young, Johnson, Steckler, Gittelsohn, Saunders, Saksvig et al. 2006). The formative research phase is also an important opportunity for the study team to begin building long-term collaborative partnerships between study communities and researchers.

Participatory mapping was developed as a data collection methodology in the field of resource management and land reform in the 1980's (Rambaldi, Kyem, McCall and Weiner, 2006). Participatory mapping falls within a broader framework of participatory research methods. Investigators using a participatory research approach engage community members in the collection and generation of information, using methods that place the locus control over data generation with the participants themselves. In participatory mapping, emphasis is placed on local knowledge and on building relations between community members and researchers (Rambaldi, Kyem, McCall and Weiner, 2006). Participatory mapping has been adapted in the field of public health to identify malaria breeding sites (Dongus, Nyika, Kannady, Mtasiwa, Fillinger, et al., 2007), garbage burning sites (McMahan and Burke, 2007) and high sexual risk areas (Power, Langhau and Cowan, 2008) and to describe patterns of health service utilizations (Rutta, Williams, Mwansasu, Mung'ong'o, Burke et al. 2005; Fletcher, Donoghue, Devavaram, Thulasiraj, Scott, Abdalla et al. 1999), and patterns of mobility that may describe the spread of epidemics(Steen, Vuylsteke, DeCoito, Ralepeli,

Gehler, Conley et al. 2000). Transect walks, or guided tours of communities with a knowledgeable community informant, have often been used in conjunction with participatory mapping exercises, to explore in more detail some of the information that emerged during the mapping process. Transect walks have been used to understand, barriers to health care access in a refugee camp in Ngara, Tanzania (Rutta et al., 2005), water use habits in Cape Province, South Africa (Motteux, Binns, Nel & Rowntree, 1999), and community knowledge of the use of tree species in Cameroon and the Central African Republic (Vabi, 1996).

Participatory mapping methods changed in the 1990's with access to spatial information technologies such as geographic information systems and global positioning systems, though the core approach remains the same namely to integrate local knowledge with "expert" data to understand the physical and social organization of places (Dunn, 2008; Glantz and McMahan, 2007). The integration of community development with the geo-spatial technologies has come to be known as Participatory Geographic Information Systems (PGIS). PGIS has been applied in a wide range of context including urban planning, managing conflict over access to land and other natural resources, resource management, and conservation and health (Dunn, 2008; Glantz and McMahan, 2007; Hassan, 2005).

We conducted participatory mapping, including transect walks, as an innovative formative research methodology prior to the implementation of Project Accept, a community-randomized trial that is sponsored by the U.S. National Institute of Mental Health (NIMH) and is designed to test the efficacy of a community-based model of HIV counseling and testing in four countries, including Tanzania, Thailand, South Africa and Zimbabwe. The community-based HIV counseling and testing model that is being evaluated through NIMH Project Accept has three major components: (1) to make VCT more available in community settings; (2) to engage the community through outreach; and (3) to provide post-test support. These components are designed to change community norms and reduce risk for HIV infection among all community members. The community-based model of HIV counseling and testing is designed to overcome barriers, including fear of stigma and lack of post-test support, to HIV testing identified through previous research (Khumalo-Sakutukwa, Morin, Fritz, Charlebois, VanRooyen, Chingono et al., 2008). Project Accept is the first international community-randomized Phase III trial to determine the efficacy of a behavioral/social science intervention with an HIV incidence endpoint.

In this paper, we report on our use of participatory mapping, including transect walks, as a methodology for overcoming the common challenges in designing and implementing a community-randomized trial. We describe how mapping was conducted in the five project sites. We then present some results from a few sites to illustrate the ways in which the methods informed the research and intervention design for the trial and facilitated the community relationship building process prior to the implementation of the intervention.

METHODS

Study Sites

NIMH Project Accept is being conducted in 48 communities in four countries, including 10 communities in Kisarawe, Tanzania, 14 in Chiang Mai, Thailand, 8 in Mutoko, Zimbabwe and 16 in South Africa (8 in Vulindlela, KwaZulu-Natal, and 8 in Soweto, Gauteng). This trial is being conducted in sites selected because they will allow for testing HIV incidence, thus allowing the study to have both behavioral (HIV risk practices) and biological (HIV incidence) endpoints. Participating sites were selected so that the average annual incidence across all communities in the study is likely to reach at least three percent. To ensure sufficient numbers of individuals to evaluate community-level change, communities of approximately 7,000–10,000 people were selected. In the context of this trial, a community was defined as a group of individuals who live next to one another and participate in common practices; depend on one another; make decisions together; identify themselves as part of something larger than the sum of their individual relationships; and commit themselves to the group's well being (Shaffer C, 1993; MacQueen KM, 2001). The communities in each site were initially selected based on existing demographic and health indicators, geographic maps, and other existing publicly available information, such as HIV prevalence data.

The study sites are all rural with the exception of Soweto, South Africa. Soweto (abbreviation for South Western Townships) is an urban area of the city of Johannesburg, Gauteng Province. Located 15km southwest of the central business district, Soweto is comprised of several townships in an area of 63 km² with a population of approximately 1 million. The second site in South Africa, Vulindlela, is a sub-district within the KwaZulu-Natal midlands region. The communities in Vulindlela are situated about 140 km. northwest of Durban, and the sub-district has a total population of approximately 400,000. In Tanzania, the study site is located in Kisarawe, a rural district of approximately 100,000 people located 30 km. southwest of Dar es Salaam. The Zimbabwe site is located in Mutoko, a rural district, with approximately 130,000 residents, located 150 km. northeast of Harare. The only Asian site included in the trial is located within Chiang Mai Province, in Northern Thailand. The study communities are located in a mountainous area between 40–160 km. northeast of Chiang Mai City.

Data collection

In preparation for the trial, each site conducted participatory mapping and transect walks to describe the physical and social organization of the communities. The participatory mapping and transect walk process had three objectives. First, these data were gathered to inform the research design, including identifying community boundaries, describing geographic and social separation of communities, and identifying relevant matching criteria. Second, data from these exercises were used to inform the intervention design, including identifying appropriate sites for the clinic-based and community-based provision of HIV voluntary counseling and testing (VCT). Finally, as one of the first data collection efforts in the study communities for this trial, the third objective of the mapping process was to build relations in the community. The intervention is designed to last 2.5 years in each community,

Prior to developing the maps, the project teams at all sites had a series of meetings over several months with administrative and community leaders from the province, districts, and more specific communities in which they were working. These meetings were designed to introduce the project to leaders and seek their permission to work in the study communities. Permission was needed at every level before finally reaching the community leaders. Information was provided on the project activities and timelines and questions were answered.

To develop the maps, 6–13 members of the community who represented various community constituents including youth, women, men and elders were selected by community leaders to participate in the mapping exercises (Alcorn, 2000). In selecting the mapping participants, leaders were asked to identify individuals who were knowledgeable about the community and whom they felt best represented these different constituencies (HIV/AIDS Alliance, 2008). The team identified an open location for the community members to draw the maps, often outside or in an empty school classroom (Mascarenhas and Kumar, 1991; Kirsopp-Reed, 1994). One member of the formative research team explained the exercise to the group, and asked the group to designate someone to draw the map, with input from others. The maps were initially drawn on the ground, using a stick, chalk or some other tool to draw the boundaries around the community, and roads within the community. The community members used other local products like shells and bottle caps to identify landmarks within the community. The community members decided what landmarks and other important attributes to include in the maps and they created their own legends for the maps. There was a designated note taker from the research team, whose role was to capture the dialogue that occurred between community members as they constructed the maps. The field notes were expanded into full transcripts after the mapping exercise was finished so that we had detailed text to analyze for the decisions on research and intervention design. The note taker was also responsible for transferring the maps that were drawn by community members on the ground onto paper after the exercise was finished. See Figure 1 for a photo of the mapping process in Tanzania.

The research teams conducted transect walks in each community after the participatory mapping exercises. Transect walks are tours of the community using community guides who are knowledgeable about their own community and who represent different groups within the community (Mahiri, 1998). The study team who conducted the mapping exercises with the community members selected 2–4 participants for the transect walks. Based on the maps that were drawn, the communities were divided into grids, and two research team members transected the grids accompanied by community members, either by foot or in a car, depending on the distances involved. As the team crossed the community a research team member asked questions about the community in the form of a mobile interview. The notes

that were taken in the field were later expanded into full transcripts for each transect walk. Tables 1 and 2 below summarizes the methods by site.

Ethics approvals for the participatory mapping and transect walks were obtained from all U.S. and international institutions participating in the multi-site trial. We obtained informed consent from all participants prior to conducting the mapping exercises and transect walks. Written informed consent was obtained in Soweto, Zimbabwe, and Tanzania while verbal consent was obtained in the other sites prior to participation.

RESULTS

In the sections below we highlight findings from the mapping exercises and transect walks at the sites to illustrate the ways in which the data were used to inform the research and intervention design and to build community relations.

Research Design

Information from the participatory mapping and transect walks were used to verify community boundaries and to identify relevant attributes for the purpose of matching and minimizing cross-over between intervention and control communities. In selecting communities for inclusion in this trial the sites had to identify attributes of the communities that may be associated with HIV incidence, and try to match paired intervention and comparison communities on these attributes. For example, it is well established that communities in closer proximity to major transportation routes tend to have higher HIV prevalence because these communities have markets and other activities that draw people from different communities and businesses such as hotels and bars that cater to these individuals. Thus, it is important in designing a study to consider attributes such as proximity to transportation routes so that they are evenly balanced between intervention and comparison communities. It is also important to minimize cross-over between communities in the intervention and the comparison arm of a randomized trial so that the true effect of the intervention can be compared to the comparison condition.

Defining community boundaries—In Tanzania, the study team learned that community members defined their communities as those pieces of land where people were living. As a result, large areas of unsettled land that were included in district maps were not always included in the maps that the participants drew of their own communities. This generated debate among community members regarding where one community ended and another began. See Figure 1 for a map that was created in Tanzania. The map includes details such as village boundaries, sub-village boundaries, graveyards, wells, bridges, schools, village office, mosque, traditional healers and secondary transportation (walking/bike) routes.

Unlike the other semi-urban or rural sites, the Soweto site is a densely populated urban site with administrative boundaries that do not necessarily demarcate natural divisions between communities. The challenge of defining boundaries was apparent in the participatory mapping exercise. In six of the eight mapping exercises, the study team reported that the participants had a lot of difficulty defining the physical boundaries of their communities. In

almost all cases the community definition of boundaries did not match the administrative boundaries found on government maps.

Identifying criteria for matching and assessing geographical separation-

During the mapping process in Zimbabwe, the investigators learned about public spaces associated with high-risk sexual behavior and health infrastructure. These factors, together with other data on population size and distance from the district headquarters, were used to match communities into pairs. To reduce the chance of cross-over between communities, the investigators knew that matched communities should not be linked through roads or bus routes, and that they needed to be roughly equidistant from the central business district for this rural area. Through the process of mapping and transecting the communities, the research team also documented how secondary transportation routes (e.g. bicycle and pedestrian trails) linked communities. The team used this information on secondary transportation routes to insure that matched pairs were not connected in meaningful ways.

Intervention Design

Researchers gathered information on potential counseling and testing sites, community mobilization strategies and post-test support options during the participatory mapping exercises and transect walks to inform the intervention design at each site.

Identifying counseling and testing sites—An important aim of NIMH Project Accept is to increase access to HIV counseling and testing in the communities randomized to the intervention arm. To do this, sites provide counseling and testing services in mobile caravans that can be driven to different venues in the community, in tents that the teams temporarily erect in venues throughout the communities, or through the use of existing community facilities such as schools, community centers or churches. The site teams used the participatory mapping and transect walks to explore potential venues for the provision of counseling and testing.

In Soweto, the research team planned to use mobile caravans to provide counseling and testing services in the intervention communities. Initially, the team planned to use empty lots that were scattered throughout communities as possible sites for their mobile provision of counseling and testing. However, after transecting the communities, the team learned that the empty public spaces that were located on the outskirts of communities were often affiliated with crime and drug activity, and thus would be one of the least desirable sites for service provision.

Determining community mobilization strategies—Another critical component of the community-based counseling and testing strategy is to mobilize communities around HIV counseling and testing to increase demand and reduce stigma associated with HIV testing. To do this, each site identified community-based volunteers and established a community working group that could be consulted as an advisory board to help manage community relations and community groups they could liaise with to promote HIV testing including women's groups, faith-based groups, etc. The mapping and transect walks helped the study

teams identify groups they could partner with for the mobilization activities, and helped them identify where to implement the mobilization activities.

The Soweto team learned about the governance structure of the communities during the participatory mapping exercises and transect walks and how to work within these structures to mobilize communities regarding counseling and testing. They learned that communities with large hostels, or dormitory like housing facilities for male migrant laborers, had governance structures that were separate from the administrative jurisdiction of the Ward Councilors found in every Soweto district. In the hostels, a Hostel Chairman and Hostel Committee carry out most local government activities. They are overseen by a traditional leader, an *Induna*, whose role is to mediate when there are issues that the Hostel Committee has failed to address or comes to a deadlock in attempting to address. Understanding this administrative/leadership structure was critical in terms of knowing how to build relations for the community mobilization process in the hostel communities.

Identifying post-test support strategies—The last element of the community-based counseling and testing strategy is the provision of post-test support for individuals who have been tested for HIV. During the participatory mapping and transect walks all sites had to identify what support services existed in the communities. Each site aimed to build on these existing services to provide post-test support services or the intervention communities.

In the Vulindlela, South Africa site, the study team identified several existing post-test support services during their mapping exercises and transect walks. They identified medical/ health services, as well as social support services that were available in communities. They created a database of all post-test support services and gave this information to the Post-test Support Services intervention team. The intervention team then went back to each organization, verified that they existed, and gathered more information on what services they provided.

Whereas in Zimbabwe, the team learned that many communities did not have access to any type of medical or social support related to HIV. There are three major hospitals in Mutoko district, one run by the government and two mission hospitals. In addition, they identified one community-based organization (CBO) that provides anti-retroviral treatment. The Zimbabwe site established agreements with the hospitals and the CBO to serve clients referred from VCT in the study communities. The project provides these referral services with additional resources to support their activities.

Building community relations

In all five sites, the participatory mapping and transect walks were two of the earliest data collection efforts for this study that occurred in the study communities. As such, these exercises represented an important opportunity for community relation building. The community members' access to project staff afforded them with an opportunity to ask questions regarding the activities and the overall study. The site teams learned about some of the emerging concerns and questions from the community regarding the project.

The types of questions that were asked most frequently during the mapping exercise fell into three general categories: 1) questions regarding the overall project, 2) questions related to how the community would benefit from the project, and 3) questions related to basic information/education related to HIV and HIV testing. Related to the overall study, community members often asked questions about how the HIV testing services would be implemented, how and when they would receive their results, and how some of these specific activities (mapping and transect walks) were related to the overall project. Related to how the community would benefit from the project, in some sites community members asked whether they would be paid for participating in the mapping and transect walk process. They also wanted to know whether the services that would be provided through the project would be offered free of charge. The research teams explained that all study related services were free of charge, and that participants would not be paid for participating in intervention services, but they would be compensated for some of the research visits. In some of the sites, particularly the two South African sites, the communities selected for inclusion in this trial had been part of other research studies. Some community members who had participated in these prior research projects were of the opinion that these earlier studies had resulted in questionable benefits for the communities. Thus, the team had to address the mistrust and suspicion on the part of these community members during the mapping and transect walks.

DISCUSSION

NIMH Project Accept is designed to change the environmental context in which people make decisions about HIV testing and HIV risk. Since the intervention is delivered at the community level, a community-randomized trial design is the most appropriate design for evaluation of study impact. The formative research phase of the trial enabled the study teams to gain a deeper understanding of the communities and to begin to build relationships of trust with community members in preparation for the trial.

Understanding how communities defined themselves both spatially and socially was critical at this early stage of the trial. Spatially, understanding the community definition of boundaries was important for the research design since the unit of analysis for the trial is the community. In some sites the community definitions of boundaries closely mirrored administrative boundaries, however in Tanzania and Soweto the community definition of boundaries were different than what appeared on administrative maps. The teams in these sites adopted the community definition of boundaries because these were believed to incorporate both a spatial and social understanding of the communities that were relevant for the conduct of this trial. For example, in Soweto through the dialogue that the mapping participants had about community boundaries during the mapping process, the researchers learned a lot about the social cohesion of these communities. In the event that there were no clear landmarks that the mapping participants could use to bound the communities, the individuals doing the mapping talked about social distinctions between individuals that enabled them to draw boundaries in very densely populated areas. Since the intervention being evaluated in this trial is hypothesized to work through community channels, understanding these social distinctions was critical to conceptualizing how the intervention may take effect in the community. In the case of Tanzania, the mapping participants never

included uninhabited tracks of land in their maps of communities. This is similar to what Dongus and colleagues found when they did participatory mapping in Dar es Salaam to identify malaria breeding sites (Dongus, Nyika, Kannady, Mtasiwa, Mshinda, Fillinger et al., 2007). They found that the mapping participants in Dar es Salaam did not include areas that were not inhabited in their community maps. In their case it was important for the researchers to include these uninhabited urban spaces such as industrial areas in their intervention catchment area because these areas included malaria breeding sites that were important targets for their intervention. In our case, the uninhabited areas that were not included on community maps in Kisaware, but the investigators did use these uninhabited areas as buffer zones between intervention and comparison communities.

Data from the mapping and transect walks also enabled to the teams to identify attributes of the community they anticipated would be related to the study outcome, and thus were important to use for matching. These attributes could not have been derived from publicly available maps or data sources. Other community-randomized trials of HIV prevention have been conducted in Africa to evaluate the efficacy of improving the clinic-based management of sexually transmitted infection (STI) control in Mwanza, Tanzania (Hayes, Mosha & Nicoll, 1995), improved syndromic management of STD (Kamali, Quigley, Nakiyingi & et al., 2003), and mass presumptive treatment of STDs (Wawer, Gray & Sewankambo, 1998). Two of these three studies employed a matched design. The investigators in these studies used publicly available information such as maps, and demographic and health data to match the communities. We were not able to find other examples of community-randomized trials that incorporated community definitions of boundaries and attributes in the research design process.

These data from participatory mapping and transect walks were also used to inform intervention related decisions in this trial. In Soweto, for example, if the team had remained unaware of how public spaces were perceived and used by community members and tried to implement the mobile testing in these venues, the uptake of services by community members would have been hindered The maps that were created by the teams continued to be used throughout the implementation phase of the project in planning fieldwork, reconsidering sites for intervention delivery, and in locating households that were sampled for the qualitative cohort.

As one of the earliest forms of data collection for this project in these sites the exercises also provided the community members with access to the project team, and thus represented an important opportunity for the project team to build community relations and respond to some of the early questions and concerns that were emerging from the community. Failure to foster community relations and obtain community input at this early stage in the research process would likely have led to problems in the implementation phase of the trial (Ziff, Harper, Chutuape, Deeds, Futterman, Fancisco et al. 2006).

We used a participatory approach to generate information about the social and geographic landscape of our study communities. We acknowledge that the way in which we implemented the participatory mapping process in the project sites did not adhere to some of the core principles of community-based participatory research (CBPR) methods. CBPR

methods have been used successfully in the past to not only generate a local understanding from the perspective of the community, but also as tool for transformation that can enable communities to address their own problems. Project based participatory approaches have been critiqued and described as technical methods of project work rather than a political methodology of empowerment (Hickey and Mohan, 2004). In the case of this study, these methods were used in the context of a multi-site randomized trial. While the trial clearly wanted to be informed by community perceptions, the ability to change core elements of the research or study design was not permitted. Some decisions relevant to the trial had been determined prior to the mapping exercises. For example, while there was some flexibility in how we defined boundaries of the communities for this trial, the sites for the trial had already been selected. Similarly, while we wanted community input on where to provide the services in the intervention communities, what services we were going to provide had already been defined. Thus, the process became community-informed, but not necessarily community-driven. Another limitation of the mapping process that we used is that the teams did not collect geographic distances to correspond to all of the community maps, thus it is not possible to assess actual distances between landmarks within and across communities. The transect walks helped the research team gain a better appreciation of distances within and between the communities. Finally, we cannot assume that the maps created by the groups in each community are representative of the entire community. We asked the leaders to select participants for the mapping exercises and gave them broad guidelines for the type of participants we would like represented in the groups. While we feel the groups were generally representative of key community constituents, some sites felt that the groups lacked representation from more marginalized sectors of the community. In future research projects employing participatory mapping exercises, we feel it would be useful to generate maps with at few different groups in the community to compare perspectives on boundaries, landmarks and other key features of the communities.

Despite these limitations, these participatory methods enabled each site to develop an understanding of their communities, both in terms of structure and attributes, that could not have been derived from existing data or data collected through standard data collection techniques. Furthermore, the methods communicated an important message to community members that their perspectives and their input are valued and necessary for the success of this research study. To our knowledge this was the first time that these methods were applied in the formative phase of a research trial to inform research- and intervention-related decisions.

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Figure 1. Photo of mapping process



Figure 2. Photo of completed map from Kisarawe, Tanzania

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Table 1

Methods
Mapping
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Con

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are selected by village lead female participants who th ir community.
r staff and village health v ty leaders.
ted participants. They se nad lived in the communi nd gender.
participants. They were a the communities, and wh s.

Table 2

Comparison of Transect Walk Methods by Site

Site	Number of guides	Mode of transportation
Soweto, South Africa	2–3 per community	Walked in 2 communities with hostels, drove in remaining 6 communities
Vulindlela, South Africa	3-5 per community	Drove in 2 communities because of inclement weather
Chiang Mai, Thailand	2 per community	Walking, except in 2 large villages they used a vehicle.
Mutoko, Zimbabwe	4 per community	Driving in all communities.
Kisarawe, Tanzania	2-4 guides per grid	Walked in the densely population regions of the communities, and drove in the regions between villages that were not settled.