Community Mobilization and Consent Seeking for Public Health Action: Experiences from the field

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Community Mobilization and Consent Seeking for Public Health Action: Experiences from the field

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Abstract

Introduction
Studies have shown that community mobilization and consent seeking are effective tools in ensuring ownership of community health programs. Most studies which have employed these approaches effectively have often led to sustained behaviour change while others have not. This paper seeks to provide information on the importance of effective community mobilization and consent seeking approaches by sharing our experiences from the field.

Methods
Two approaches were used to generate data: a review of relevant literature and the authors experiences in the consent seeking and mobilization process. Search engines used were PubMed, google as well as the review of policy documents.

Results
Findings showed that different authors employed different methods for community mobilization which include group mobilization approaches, group discussion meetings, training workshops, community member peer data collection, phone calls, financial incentives etc. Most authors combined these methods.

Consent seeking methods were mainly oral, written or proxy and most of the studies had an ethical approval from a Research and Ethical review Board.

Conclusion
There is still need to harmonize these approaches especially for ethical purposes. Single or independent approaches to mobilization and consent seeking may not only be efficient if expected results are to be achieved but are crucial. However, whichever approach adopted should consider the context, content and actors involved in any given project. Note that experiences with these approaches may vary in the field.

Introduction

In every study or intervention, whether it is designed to make policy, to better improve practice or to evaluate outcome, must consider community involvement and participation [1-3], and this therefore depends solely on community mobilization and consent. Studies have shown that community mobilization and consent seeking are effective tools in ensuring ownership of community health programs [4]. Health interventions and development efforts to reach the at-risk populations are possible through employing these means.

Community mobilization can be defined as a capacity-building process through which community members, individuals, groups and organizations plan, carry out and evaluate activities on a participatory and sustained basis to achieve an agreed upon goal, either on their own initiative or stimulated by others [5]. It encompasses a range of interventions, approaches and styles to effectively pass on information to the community leaders, religious groups and other community members [6]. It is also a process of organizing people to be ready for action or rather to take action especially for matters concerning the entire community. Studies have found that a lot of community mobilization approaches have been used in many country-wide studies with proven success and hence plans to scale up and integrate its use in broader national health strategies are underway [7-8].

Consent seeking on the other hand has been a contextual issue globally following the Helsinki declaration in 1964 which was revised in 2008 [9-10] and is central to any research process at any level especially when research involves humans. It represents a process of getting a study participant, interviewee, study subject or the community members involved in a study or intervention to officially and voluntarily give a verbal or written agreement before the interview is granted to him or before he is assigned to a study group [10-11]. Report in Nigeria has also established that consent seeking is an ethical issue attracting sanctions for offenders, and gave consent seeking a prominent position in health research in Nigeria [12]. Also the first specific declaration on the protection of human subjects during research was made by the Nuremberg Code and it declared that the voluntary consent of human subjects is absolutely necessary [13-14]. These led to the establishment of the Research and Ethical Review Boards across the country. Other studies have also reported that consent seeking for health research especially with human
persons is a tenet for assessing governance in health policy reform [15-20]. It is important to note that this decision by individuals to participate should be voluntary without subjection to coercion, undue influence or intimidation. Studies on children would require parental or guardian’s consent [13]. Special attention should also be given to women who due to gender based issues are relegated to the background and hence the issue of consent and confidentiality are often violated [21]. In this case, their husbands are required to make decisions for them. Most studies however do not need consent since they do not carry much risk e.g. descriptive studies that would need extraction of information from the medical records but the record keepers would need to give permission to allow use of information [13]. The same goes for the decisionally impaired groups e.g. comatose or the mentally ill patients. Only the members of the research team and stakeholders who can use the data to the benefit of the participants can handle the information.

However, a good number of studies have recorded different approaches to community mobilization and consent seeking [1-3, 22-25], and these approaches and their corresponding results are presented in the result section. Some of these studies showed sustained behaviour change [1, 8, 25-26], while some did not. Some authors have also posited that community mobilization processes facilitate or impede community uptake of a programme or intervention [27-28]. However, no study in Nigeria has investigated the prevailing community mobilization and consent seeking approaches and how these enhance or impede community participation and involvement, and invariably health programmes. This study therefore hopes to fill this gap in knowledge by drawing largely on lessons learnt from the field.

Methods

Two approaches were used to generate data: a review of relevant literature and the authors experiences in consent seeking and mobilization process. Systematic review of literature, interview documents, study protocols and tools, and grey articles was conducted. In all, forty-five documents were retrieved, but only thirty of them were included in the review. Documents were reviewed if they utilized informed consent and community mobilization approaches. Policy documents were also reviewed. Verbal consent in this context could be obtained through individual, group, community. Community mobilization methods used by the authors included phone calls, text messages, advocacy workshops, letters, abridged forms of proposal protocols, electronic mails, town criers, use of focal persons. Data generated from the published documents were compared with lessons learned by the authors in similar projects upon which recommendations were drawn. The search engines used were Google, Biomed central, Pubmed and Yahoo. Key words used for the search were community mobilization, consent seeking, ethics, community participation and involvement, Nigeria.

Nine [9] projects in which the authors were part of were reviewed. We reviewed methodology guidelines for the projects and posited our experiences. Below were the studies reviewed:

1. Listing of Primary Health Facilities, kindred, Community Directed Distributors, patent medicine dealers [PMVs], and Community Laboratories in Anambra State. The objective of the listing was to provide accurate and up to date information on all Primary Healthcare facilities (PHFs), Kindred groups, Community Directed Distributors [CDDs], mini-labs and PMVs in catchment areas of Primary Health Facilities which will serve as baseline information for implementation of Community Systems Strengthening [CSS]. This would provide the necessary information for the implementation of the CSS component in Anambra State. This was a World Bank funded project.

2. Assessing the social and economic impact of onchocerciasis and Filariasis on households in Oji River LGA. To generate new knowledge about the social and economic impact of Onchocerciasis and Filariasis, two neglected tropical diseases, on households so that the magnitude will be clear to policy makers in developing policies, prioritizing intervention programmes and ultimately improving the lives of the affected individuals.

3. Effectiveness and cost-effectiveness analysis of alternative strategies for the deployment of Artemisinin Combination Therapy at community level in Enugu state, southeast Nigeria. The objective was to increase availability and use of ACTs in Nigeria, and to improve provider practices and consumer behavior for the treatment of uncomplicated malaria. This was a CREHS project funded by DFID.

4. Cost benefit analysis of malaria preventive interventions in Enugu state: comparing indoor residual house spraying, ITN and larviciding. This study investigated the costs and benefit of the malaria preventive interventions by seeking peoples’ willingness to pay.

5. World Bank/Enugu state Insecticides Treated Bed Net Campaign in Enugu state. This project distributed 2 free nets to 1 household during the campaign. This
was aimed at achieving universal coverage for health.

6. Access and utilization of routine dental treatment among different SES groups. This study was both a hospital based and community based survey.


8. Examining the links between accountability, trust and performance in health service delivery in Orumba South Local Government Area, Nigeria. The objective was to find out what makes the Health Facility Committees functional and to gather information on issues such as the linkages between the HFCs and the community, the pattern of engagement between different community groups and the accountability structures’ perceived impact on health service delivery.

An Impact Assessment of the Role of Informal Health Workers in Scaling Up Exclusive Breastfeeding among Mothers In Ezeagu Local Government Area- A Health Intervention Study. This study aims to find out how the Informal Health Workers (IHWs) can be used to train mothers on the importance of exclusive breastfeeding after they had been trained. Findings will help policy makers to empower and probably extend their services to other areas especially the remote rural areas where there is no doctor.

Results

Community mobilization

Literature review showed that communities were mobilized in various ways. Most projects utilized group mobilization approaches than individual approach. Approaches to community mobilization varied across communities and projects. These included group discussion meetings, training workshop, using community members as co- trainers in the workshops, public meeting with the stakeholders, church congregations and women organizations; advocacy meetings and consensus building, setting up steering committee; using community members as data collectors; contact telephones, financial reward; certification; integrated organizational approach; community action cycle, involvement of local health workers and marginalized groups; and involving the community in the evaluation process. However, most projects combined more than one approach to mobilize the communities for action.

In all the projects undertaken by the authors in the study area, a combination of approaches were undertaken to mobilize the participants. These approaches included repeated phone calls, sending SMS to the stakeholder and concerned individuals, advocacy workshops, letters, given abridged copies of the study protocols to the expected participants, and advocacy visits to the stakeholders and other incentives such as transport allowance. Other approaches included sending email messages to the people, use of town announcers to inform the community, use of focal persons, training workshops, face to face discussions, and mobilization through opinion leaders.

Consent seeking

Literature reviewed showed that not all projects sought consent. Some of the works sought informed consent, although it was not clear whether the consent was oral or written. There were evidences that most of the projects sought ethical approval from the Research and Ethical review Board. However, information on ethics and consent was totally missing in some studies. Meanwhile in some cases, proxy consent was sought, for example, in one of the studies; consent was sought from the parents of the children who were under 18 years participating in the study [25]. Consent seeking was for group and individuals and at times both were combined.

The authors however sought consent in all the projects they conducted which were for the analysis. In most of the projects, consent was sought through both oral and written approaches. Information sheets explaining facts, confidentiality, risks, benefit for participation, contact details of investigators or projects managers were first of all given to the participants who were educated. In cases where the participants were not educated, the process was explained to them and their thumb print was taken and in this case a witness validated the consent either by signing or by thumb printing on behalf of the participant. In some of the studies, consent was sought from a group, individually and just in one occasion by proxy where school children were used as peer health educators to reach the communities, consent was sought through the school management.

Discussion

Most of the projects used a combination of approaches to mobilize and seek consent from the community. These approaches evidently increased participation and success in the projects and helped sustain the interventions in question [1,4,10,22,24,27,28]. However, this work did not seek to investigate the degree of participation and success achieved in the studies. Different approaches have different capacities for mobilizing community action but in some way would have to be combined for maximum
effects.

When employing any approach for community mobilization, care should be taken to use the most appropriate means or medium for a particular community or setting. As shown in the results, many health actions which lead to sustainable change in behaviour have succeeded largely through a careful combination of approaches to community mobilization and informed consent. This seems to be due to the fact that they provided a platform for the transmission of information to targeted groups within their local contexts(29). Studies in other countries have also demonstrated the effectiveness of these approaches [community mobilization and consent seeking] and found that it reinforced community knowledge (3, 30).

This paper discusses experiences of the authors from the field which somehow criticized some of these approaches. The experiences showed that some of these approaches to community mobilization and consent seeking can either impede or enhance the uptake of a programme or intervention.

However, analysis of the related literature review showed that there is a slight shift from the traditional approaches to mobilization and consent seeking. For example, the authors used repeated phone calls, email letters, SMS, giving abridged copy of the study protocols to the expected actors to get quick access to the stakeholder. These approaches have a way of putting the receiver on the ‘toes’. On the other hand, there is evidence of a third party in consent particularly for persons who are not literate to sign the consent form.

Nevertheless, literature indicates that not all projects sought consent. But then, it is possible that those projects sought consent but missed the information in the report. This is an issue of concern to research ethics since the risks and benefits for participation could not be tracked. This then is against the Helsinki declaration and the national health bill of Nigeria [12]. There is therefore need to address this issue particularly during conferences and workshops. One way to curb this situation is to stop publishing works conducted with human person which did not seek consent. The research and ethical review board should strongly enforce that researchers applying for ethical clearance must come with information sheet and consent forms attached to the abridged copy of the study protocol.

Experiences from the field.

In the first project primary healthcare facilities (PHFs) were the entry points into all the communities and they also provided the number of community-directed distributors (CDDs) serving each community. Triangulation was used to obtain the information on the number of kindred in each community. For the patent medicine vendors (PMVs) and community labs, a snowball approach was used to list all of them. Oral consent was obtained from respondents after duly introducing the purpose of the listing, at the primary health facilities; consent was obtained from the officer in charge and in their absence a representative health worker. Obtaining consent from PHC workers was easy and straightforward, once the purpose of the exercise was explained; health workers at the PHC level do not refuse consent probably because the consultants were from the governments.

Obtaining consent from the PMVs was more problematic; majority feared the purpose of the listing. They were mainly nervous and their presumption was that the programme aims at finding new methods of throwing them out of business. Majority of the PMV’s seen refused interviews until they saw authorized letter from their president or they obtained approval by telephone from their leaders. Most of the PMVs found it difficult to give consent to the interviews as loyalty to the PMV association was high; hence they all try to contact their local leader before granting any interviews. In few occasion, the PMVs would run away even in the presence of the enumerator, or would dodge if he gets the sign that the enumerator was around. Sometimes, they tended to deny ownership of the shop.

In the second project, two villages were selected for inclusion in the study. The community leader and village heads were contacted and briefed on the objective of the study. Households were screened for the presence of any individual with observable onchocercial and filarial manifestations. Those households were selected for the administration of the questionnaire. Written consent was obtained before administration of the questionnaire. Information sheet was however given to the households to ensure better understanding.

Due to the sensitive nature of the subject, recruited field workers were not allowed to work in the particular village they come from. This is because people may not want to disclose their symptoms to someone they know because some aspects of the diseases in question are associated with high levels of stigma.

In the third project, the project involved intervention design and implementation for providers [health] workers and consumers. Advocacy visit to the stakeholders was first conducted [ministries of health and education, commissions, relevant parastatals, schools, health centers PMVs and pharmacies and
other allied civil society organizations]. During the visits the abridged study protocol with information sheet attached to it was given to each of the stakeholders mobilized. Usually, the heads of units/facilities were the entry points.

Most often we gave the actors calls and rapid SMS to inform them of our coming. Series of stakeholder meetings and workshops were held, and tea break and lunch accompanied each meeting/workshop, and stipend [transport allowance] was given to them. Invitation letters were also sent out prior to the workshop date, and sometimes health policy Research Group which is the coordinating unit would organize capacity building in technical areas and policy analysis. Training workshops were held severally for all actors involved in the implementation of the intervention designed. For the community intervention component of the intervention, schools were mobilized to give them the message through peer health educators. However, community members were invited to the school health malaria events through town announcement.

We noted a high turnout with all these approaches, gaining maximum support, participation and involvement of the community members at large. However, some of these strategies were time consuming. For example, it may take a long time to meet a stakeholder in the office, or even take some days before one sees them. Sometimes letters got missing on the way especially when the expected stakeholders were not in the office, their subordinates would withhold the letters thinking the workshop will yield a huge sum of money.

Although calls and SMS were effective in mobilizing actors, it was cost escalating. In addition, it was realized that the use of undependable communication networks in Nigeria might create a legitimate alibi for non-compliant actors and make it difficult to reach cooperative ones. Otherwise, it would be an anchor for those who do not want to honor the invitations. However, important actors might be missed out of the way. These approaches however, although possessing the capacity to reinforce mobilization, should be used with caution. For example, we noted that calling contact persons on phone to mobilize study participants created some chaos as the contact person misinterpreted the information and invariably invited more participants than required. It is then obvious that phone calls and SMS may not give clear understanding of the objectives to the contact person, rather, may just serve as a reminder.

We noted that town announcers are very effective in the rural communities owing to their undiluted, integrated and extended family life. In some occasions, community members who did not come out when the announcers beat the gong would oblige to pay a stipulated penalty. Financial reinforcements especially for persons coming from a very far place aided mobilization, except that it was cost escalating, and the money could be channeled to more cost beneficial aspects of the project.

Ethical clearance was sought for the project. In addition, endorsement letters were collected from the ministries of education and health. Informed consent [written] was also sought accompanied by an information sheet. Informed consent was sought at facility, local health authority and state levels and at all phases of the project implementation. There were not many issues with this as people who we sought consent from were mostly literate, except for the patent medicine dealers who would always exhibit or portray fear and loyalty to the association of PMDs. Therefore consent is much easier with the literate sector.

Challengingly, some heads of local health authorities who may have expected some financial aid but were not selected to be part of the implementation team tried to deny knowledge of the project and as such made moves to stop their colleagues from participating. This could be because the government kept changing heads, permanent secretaries and programme officers. These issues were also brought up during briefing meeting with ministry of health. However, ethical clearance and endorsement letters facilitated consent with the PMDs who normally asked for approval from their associations.

It was also challenging then to get the private health providers [PMVs and pharmacists] to come for the training workshop even with accompanying tea break, lunch and transport allowance. This group of actors proved hard to retain throughout the training programme as they always complained of valuation of their time lost to money. Nonetheless, the experience in the fourth project shows households feared consent because they thought they were to pay for the proposed items under evaluation.

Meanwhile the mobilization approach used in the fifth project was use of net cards. This enhanced community action in terms of coming out to collect insecticides treated bednets. However, in a very remote community in the state, community members drove out mobilization officers probably because then was election period and the community members thought the mobilization officers came for campaign. But when they realized that they were missing out benefits, they called for a second chance. This agrees
with other work in India in which appropriate information increased participation and consent [7]. Again, information sheets did not accompany net card and the mobilizers were not adequately trained to do the work. Although the mobilizers were also community members residing in the same community, town announcers communicated the exercise to the community members before the issuance of net cards.

In the sixth project which was to estimate the burden of malaria in Nigeria using the cost of illness approach, Letters together with the abridged protocol of the study was sent to the chairman, the Head Of Department of Health and the Malaria control manager all of Oji LGA to inform them about the study about to be carried out in their LGA.

We went personally to see the above people and explained the nature and purpose of the study and the groups carrying out the study. A letter granting us permission to carry out the study was extracted from them.

The team then carried out advocacy visits to the community leaders, Church leaders and Heads of health facilities being used for the study. We also enclosed a letter, and an abridged protocol. We had face to face discussions with them and also showed them a copy of the letter of approval from the chairman. This visit enabled the team members sensitize these key people in the community about the purpose of our study. In addition, these visits made it possible for announcements to be made in the communities and churches so as to enable the people to be receptive to us, to welcome us into their homes and respond to the questions as openly as possible.

We approached each of the community leaders with bottles of hot drinks and kola nuts which were presented to them by the males in the team. After presentation of our gifts, we then explained the purpose of our study and sought his permission to carry the study out. On the part of the health facilities, Heads and in that way mobilizing the areas and people about the study and all their questions were answered.

The first step in mobilization and sensitization to the study started during the enumeration. As the households were enumerated, they were told briefly about the study. Meanwhile, when the study started the household heads who not present during the enumeration claimed not to know anything about the study and so were either uncooperative, or we had to explain the whole study again. We tried to mobilize the household heads and in that way mobilizing the areas and people we were going to carry out the study on.

We paid advocacy visits to the heads of the facilities involved in the hospital survey. A letter was drafted and attached to an abridged copy of the protocol. This was given to the heads by hand and a face to face discussion about the study took place. Verbal consent was given by the heads of facilities. When interviewing the patients, informed written consent was sought prior to the interview.

The eight study was community based and we had to interview. Before interviewing a respondent, the aim and purpose of the study plus the benefits and risks of the study were explained to the respondent. They were also given the opportunity to ask questions concerning the study. When this has been clarified, we obtain a verbal consent from them. They were then given the written consent form which is read out to those who cannot read and they are then asked to sign. For those who cannot write, they were asked to give a thumb print in the presence of any witness.

The consent form was administered to individuals. After signing the consent form, a copy of an information sheet explaining the study and the ethical rights of the participants to choose whether to continue the study or not was given to them. The information sheet also contained the phone number and address of members of the research team.

Some respondents still refused to sign the consent form, either because they were afraid, thought we had an ulterior motive for conducting the survey, or were just not interested in the study. Some respondents only agreed to sign after the interviews have been done. Some respondents refused to write their names on the consent form for fear of being identified and put down only their signatures even though we had assured them about the confidentiality of their information.

The seventh study was both a hospital based and community based survey which evaluated access to and utilization of dental services in Enugu urban. Considering the fact that the study was done in an urban area, there was no community leader to visit. The first step in mobilization and sensitization to the study started during the enumeration. As the households were enumerated, they were told briefly about the study and all their questions were answered.

We obtained both verbal and written consent prior to
obtain consent by using letters and an abridged form of the proposal which were sent to the Local Government Chairman, traditional rulers and other opinion leaders of the chosen areas. They informed the health facilities that we were coming for a study. The study had to do with exploring the functionality of the Health Facility Committees (HFCs) and finally report our findings to policy makers to enable them use the information to enact policies that will help to empower these HFCs towards better health service delivery for the communities. Furthermore, we explained the purpose of the study to the Health Facility Committee chairman and the Officer-In-Charge after which it was easy to obtain verbal consent for our in depth Interview (IDI). We also used tape recorders to facilitate transcription which they also agreed to. This we did for all the key persons who we had to interview.

For the community mobilization, an intimate contact with the community members was required, therefore in each site a researcher and two field workers were required to stay in the community for a minimum of 30 days for the duration of the study. This was part of the strategy towards community mobilization as well as to get the local contexts of the community. This was necessary because our study was purely a qualitative study and Focus Group Discussions and Indepth-Interviews were required. We also observed health worker practices and the functioning of facilities to validate our data.

The challenges we had was that our presence stirred up some kind of tension in the community and made some of the communities to establish some ad hoc HFCs. They thought we wanted to give them some material gifts e.g. money, equipments etc. By the time the community started getting a feel of what our mission was, they felt free in participating in the exercise. We utilized another tactics such as paying unannounced visits to their meetings for observation. We also had to mobilize the traditional rulers with gifts like hot drinks and kolanuts because titled men should not be seen empty-handed in the study area. The challenge in this situation was that the traditional ruler does not live in the community and could not therefore mobilize his subjects. We experienced beaureaucratic problems in following due protocols with his cabinet members. This affected mobilization by delaying our programme.

For the 9th study, informed consent was obtained from the mothers verbally without problems because most of them were literate and felt they needed the programme. The community members helped in mobilizing others through their church meetings, women group meetings etc. Prior to this, ethical clearance for the study was obtained from the Research and Ethics Committee. The challenges were obtaining consent from the mothers who were illiterate and who were deeply influenced by their beliefs against exclusive breastfeeding.

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