COMMUNITY PARTICIPATION IN ESSENTIAL NATIONAL HEALTH RESEARCH PROCESS: Uganda's Experience

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UGANDA: FACTS AT A GLANCE

Socio-Economic Indicators of Uganda

[1] Currently the population of Uganda is estimated to be 19, 572, 583 of which only 2,670, 546 (13.6%) is urban. Total number of households is 3,434, 177, mean household size is 4.8 and mean number of persons per room is 1.9.

Percent of households that are:

- female headed 28.5%
- headed by children 1.1%
- have only one member 12.8%
- own a cottage industry 23.6%
- depend on subsistence farming for a livelihood 69%

Percent of households which have:

- access to electricity for lighting 5.6.%
- non-wood fuel for cooking is 1.6%
- access to safe water 34%
- no access to toilet facilities 28.6%
- no kitchen 36.4%
- no bathing facilities 50.6%

Percent of dwelling units which are:

- made of temporary materials 58.6%
- less than five year old 42.8%
- Owner occupied 81%

[2] By 1995, Uganda's income per capita was US $ 220.

[3] By 1992, the population of Uganda in absolute poverty was 57% for rural and 38% for urban.

[4] By 1993, 55% of Uganda were found to be living on less than US $ 6 per month.

[5] Infant mortality rate is 97 per 1000; total fertility rate (per woman) 6.9%;

[6] Maternal Mortality rate 506 per 100,000

[7] Life expectancy at birth is 45.7 years (male), Female 50.5 years.

[8] By 1993, adult illiteracy was at 41.3% overall and 52.3% for females.

[9] By 1991, over 80% of children (6-12 year) attended primary school, but only 12% of older children were at school.

[11] Between 1970 and 1996, Uganda's human development index increased only from 0.213 to 0.326; Uganda ranked 154th on this index out of 173 countries

[12] Over 75% of total households in the country are smallholder peasant farms found mainly in the rural areas.

[13] 56% of agricultural GDP is from subsistence production.

Sources: Adapted from:

[1] Uganda Demographic Health Survey 1995

[2] UNDP/Ministry of Planning and Economic Development (1995) HIV/AIDS Prevention and Poverty reduction Programme Uganda. UGA/95/001. Kampala: Lakeside Publishers

1.0. Introduction:

1.1 The Concept of ENHR

ENHR is an integrated strategy for organising and managing research, whose defining characteristics include its goal, its content and its mode of operation. ENHR's goal is to promote health and development on the basis of equity and social justice. Its content includes types of research such a epidemiology, social and behavioral research, clinical and biomedical research, health systems research and policy analysis. It emphasizes the problems affecting the populations especially the poor and disadvantaged. The mode of operations on the other hand is characterized by inclusiveness, involving researchers, health care providers and representatives of the community in planning, promoting and implementing research programs.

The movement in support of Essential National Health Research aims to orient health research to the specific needs of each country. ENHR involves strengthening the country's ability to identify problems, carry out research, and apply the results, in order to promote health and development on the basis of equity and social justice. The community is considered one of the three major stakeholders in ENHR, and community participation is named as an important part of the ENHR Strategy for Action (Task Force 1991:4). The Strategy includes seven elements: Promotion and Advocacy, ENHR Mechanism, Priority Setting, Capacity Building and Strengthening, Networking, Financing, and Evaluation. Community participation is considered important in at least some of these elements. Moreover, the actual research carried out as part of ENHR may be expected to involve community participation.

1.2. Community Participation in ENHR

Since the 70's community participation in health has been a major subject of policy. It was a fundamental ideal in the Alma Ata Declaration of 1978, and twenty years on, it is still considered an essential part of health development. But today there is growing recognition that community participation is a complex process. (Jewkes and Murcott 1996; Zakus and Lysack 1998). One problem is that the terms themselves are broad; they can refer to a wide variety of phenomena and are often used loosely, without specification. A second problem is that, although community participation has been adopted as a universal ideal, its implementation in practice is shaped by national and local situations. The possibilities and realities of community participation are country specific.

A basic principle of ENHR is that it involves a partnership between three categories of actors: policy and decision makers, researchers, and communities (Task Force 1991:25). The community"seems to be synonymous with: the public, the population, people in general, users of health services. In contrast, when the term "community" (participation) is used in research projects or local health initiatives, it often refers to a

narrower, territorial sense of community - people who live together in a village or a city neighbourhood, people who work together in a work place.

This study examines how "community participation" is understood in particular situations, in relation to specific goals and activities and partners. For example, the first element of the ENHR Strategy, promotion and advocacy, includes sensitizing "the public at large" through appeal to NGOs, women's groups, traditional healers, and others (Task Force 1991: 13-14). The fifth element, networking, can involve dissemination of research results within the country, to policy makers and the public (Task Force 1991: 36). Ideally, the ENHR mechanism includes representative of public interests and concerns. In priority setting, "people in general" should be consulted (Task Force 1991: 24). Thus, in these activities, "community participation" refers to different ways of being involved in reciprocal relations: planners/researchers sensitize and people become aware and interested; researchers inform about their work and the public learns; policy makers consult about priorities and people express their views and explain their needs.

The social entities with whom planners and researchers interact in these strategic elements could be of many different kinds: members of the public reached through the media; interest groups; committees; people chosen to participate in focus groups; local residents called to a meeting, etc. Relations can be fleeting, intermittent, or long-term. Research itself, when it is carried out upon or together with a group of people, may involve modes of participation including: co-option, compliance, consultation, cooperation, co-learning, and collective action (De Koning and Martin 1996). Essential National Health Research projects may vary widely in the extent and mode of collaboration between researchers and the communities where the research is carried out. A long-term research programme in a delimited geographical area offers opportunities for relationships to develop. But even in such programmes, full community participation, for example in defining research goals, is difficult to achieve (Seeley et al. 1992)

Community participation in ENHR must be understood in relation to its country context. The changing political scene, the role of international donors and programmes, economic conjunctures, the history of state demands on citizen involvement in development, the extent of social differentiation - all of these and many other factors are relevant for the potential and fate of community participation (Morgan 1993). Some countries have a lively media, a well-educated public, and a civil society characterized by a multitude of interest groups that are engaged in debates about health and health research. In others, poor, rural, or uneducated people may be little aware of the concerns of researchers and policy makers. In each case, community participation in ENHR must be related to larger social and historical processes.

1.3 The Problem

Despite the importance attributed to it, there is little systematic knowledge of how

community participation actually functions, or could function, in ENHR. We do not know how community and participation is understood in different contexts. Therefore, the Council on Health Research for Development has called for a study to examine how community participation has been defined, understood and practiced in countries trying to implement ENHR. The focus will be on community involvement in the various elements of ENHR (promotion and advocacy, priority setting, etc. and also on community participation in the research itself. The goal is to examine possibilities, discuss problems, and find fruitful ways of including the third stakeholder in ENHR.

1.4 Objectives of the multi-country study

- to find out what community participation in ENHR has in fact meant in selected countries that have implemented the strategy.
- to document examples of community involvement in ENHR in order to show modalities worked out in different countries
- to use the examples to discuss problems as well as best practices
- to extract lessons learned

1.5 The significance of the study

There are several reasons for concern with community participation in ENHR:

- **equity** in health requires the involvement of all components of the population, especially those who are marginalized
- **political support and sustainability** of ENHR depends, at least partly, on popular understanding and commitment
- **use of research results** for change requires people's own initiatives and better awareness and knowledge
- **excellence in public health research** is achieved through engagement with all categories of society, and attention to the variation in social contexts of health and health care

The basic principle is that health and health research are not, and cannot be, the exclusive concerns of professionals - policy makers and researchers. The study show these ultimate goals of ENHR have been pursued through different modalities of community participation. It will provide suggestions for further efforts to bring people - the public, local communities, interest organizations, representatives of disenfranchised groups - into Essential National Health Research.

1.6 The Study Framework

The study focused on community participation in:

(a) activities/elements of the ENHR Strategy; and

(b) selected research projects under ENHR.

The elements of ENHR where community (public) involvement could be relevant are: promotion and advocacy, the ENHR mechanism, priority setting, and networking. In addition two research projects that are considered to be in the spirit of ENHR were chosen for study.

The study has three aspects:

· description
· assessment
· contextualization

The description of community and participation was concrete and specific, relating to particular activities (consulting, informing, planning, learning, mobilizing, etc.). The assessment included the evaluations of the different parties involved, as well as the analysis of the researcher. It focused on the process and the outcomes, the strengths and weaknesses. The contextualization was important as it placed the efforts at community participation within the country situation i.e its political history, economic circumstances, development efforts, social organization, health conditions, and research traditions. Key research question revolved around three basic pertinent issues of describing community, describing participation and assessing community participation.

1.7 Methodology

The study was basically qualitative and involved documents review and field research. Data collection techniques used included:

a] Key informant Interviews

The interviews were conducted with stakeholders at different levels.

At national Level

Task force members who were involved in setting up the Essential National Health Research (ENHR) in Uganda and the researchers.

At district level:

District officials:

- the District Medical Officer (DMO) of the areas of study
- The District Health Team

Political:

- Local Council Five (LC5)

- Local Council three (LC3)
- Local council one (LC1)

At Community/parish level

- Members who were involved and participated in the research, and community leaders.

b] Group discussions

These were basically with the community beneficiaries or participants in the projects. A list of respondents is in the annex.

c] Observations

Observations with checklist were also used when visiting some of the sites in the field to find out what was actually done.

d] Documents review

A number of documents on community participation, ENHR and project documents were reviewed. projects visited.

Site selection

The Uganda advisory group met and decided on the sites to be used as cases in community participation in research. In addition Professor Susan Whyte a reknown researcher on Uganda advised accordingly from time to time.

The suggested sites included:

i. Utro - trypanosomiasis research in Bugiri district, Eastern Uganda

ii. Pallisa Community Development Trust (PACODET) in Pallisa district, Eastern Uganda

iii. Mpererwe Community project, a peri-urban project in Kampala district.

The Instruments:

Key informant and group discussion guides were developed to cater for the kinds of respondents to be interviewed. These were developed from the study framework in the generic proposal for community participation: multi-country study.

2.0. The Country Context

2.1. Socio-economic context

Uganda is one of the east African countries lying astride the equator. It covers an area of 241,038 sq.km, one-sixth of which consists of lakes, rivers and marshes. Half of lakes Victoria and Albert are in Uganda. Uganda is basically elevated basin ranging from 1000 to 1400 m above sea level, in between the East African and Central African rift valleys. It borders with Kenya in the east, Sudan in the north, Rwanda in the south, and Zaire in the West. Most of Uganda is Savanna grassland with few pockets of tropical rain forests. Rainfall averages from 500mm in drier areas of the country such as Karamoja to 2,000 mm in the fertile areas of lake Victoria basin. The country is divided into four statistical regions namely, central, eastern, northern and western and has 45 decentralised administrative districts. Each district is further divided into counties (on average about 4 counties per district), sub-counties, parishes and lastly villages. At the grassroots there are about 40,000 villages (UNFPA, 1997).

As per 1991 Census, Uganda had a total population of 16,671,700, but now estimated to be already 20 million, with an annual population growth rate of 3.0 %. Such high growth rate makes the age structure to be youthful with 47% of the population below 15 years of age and almost 75% below the age of 30. About 85% of Ugandan population live in rural areas, and 70% depend on agriculture. The Average family size is 4.8, and 26% as female headed households of the total household (Barton and Wamai, 1995., UNFPA 1997).

Most development indicators of Uganda are low and shows that the infant mortality rate (IMR) is 97 per 1,000 births, and under five (U5 MR) is 203 per live births. Total fertility rate was 7.1 children per woman in 1991 Census but according to the Uganda Demographic and Health Survey (1995), fertility had declined slightly with a fertility rate of 6.9. Urban women have a fertility rate of 5 births per woman while rural women have 7.2 children per woman. Women with secondary education have much lower fertility of 5.2 than those with no education or primary education (7.0 births). By the time women reach 19 years over 70% have either given birth or are pregnant with their first child. Despite fertility preferences being high ideal family size among women has significantly declined from 6.5 in 1988/89 to 5.3 in 1995. Results from this survey show that 22% of births were unplanned so if unwanted births were eliminated the fertility rate in Uganda would be 5.6 births per woman instead of the actual fertility which is 6.9 (Statistics Department, 1996).

The population density is about 84 persons per sq.Km which is quite high in comparison with other East African Countries (Kenya 43/sq.km, Tanzania 29/sq.km). Total literacy rate of the district is 54%. Female literacy is 45%, while male literacy is up to 65%. Only 34% of the population nation wide have access to water. At least 57% of the rural population live below the poverty line (UNFPA, 1997).

The turmoil that affect the country between 1979 and 1985, left it stagnating, reduced outputs from agriculture and industry, accumulating state debt, collapsed formal sector and the general corruption of the state. This also affected seriously the growth of the economy and the provision of social services such as education and health care. The government has embarked on a Poverty Action Plan which seeks to reverse the poverty situation through strengthening of core development programmes such as education, health road maintenance, law, order and security.

2.2. The Economy

Uganda's economy is based on agriculture (60% of GDP is from this sector, and about 98% of export earning, and about 40% of government revenue). Most of the farming is labour intensive and is peasant farming with coffee as the main cash crop. Other cash crops include cotton, tea and rice. Food crops varies from district to district but include millet, bananas, cassava, beans, groundnuts and sweet potatoes, Maize etc. Women provide about 60-80% of labour. They are mostly involved in food crop growing than cash crops which was traditional men's crop. land ownership and use are key determinants of agricultural activity, income and security. In Uganda, men control the land despite women being the principal source of agricultural labour. Only 7% of women own any land (Barton and Wamai, 1995).

Uganda had inherited a good colonial economy in 1962 but this was reversed during Amin's regime in 1971 and by 1980 the GDP had dropped by 18.8%,. By 1986 inflation was high and measures were taken by the government and an agreement was reached IMF and World Bank for Structural Adjustment Programme. Tax base has been low hence there had been a tendency to rely on external aid to meet public spending which has had effects on social services such as health and education, making the most vulnerable groups such as the women to suffer. Uganda is ranked 157th on the 1996 UNDP Human Development Index out of 174 countries. Its capita income for 1995 was US$ 220 (UNFPA, 1997). Because of insecurity that characterized the 1970 and 80's there was a lot of out migration. Uganda also lost most of its professionals looking for greener pastures. The change of government in 1986 brought peace and a number of people came back to Uganda. Of late many refugees have settled in Uganda from neighboring Sudan, Zaire and Rwanda running away from civil strife and unrest.

In Uganda, the prevalence of HIV infection still remains high despite the recent findings of declining trends seen at some antenatal clinics in urban centres (from about 29% to 18%). It is now estimated that as much as 11% of the adult population may be already infected.

AIDS is the leading cause of death among adults between 15-45 years; the majority of HIV/AIDs cases, about 83 percent, are young adults in the age group 15-45 years. The depletion of human resources both in rural areas and urban centres is therefore quite evident.

Uganda is composed of many tribal groupings of Bantu, Nilotics, Nilo-hamites and the Sudanic groups. Most people in central west and south are Bantu while those in the north, northwest and north east are Nilotics and Sudanic groups. Rural areas are much poorer than urban areas, with the northern part of the country being poorer than the south. Women are worse off than men basically as a result of limited rights and access to income, property and education. A number of vulnerable groups include orphans, disabled, older people, refugees and the minority ethnic groups such as the Batwa (pigymies of southern Uganda).

There is considerable geographical differences and inequality. This is shown by substantial variations across many key indicators in Uganda. The language, economy, social and marriage traditions are quite different. The most affected regions of the country is the north and the North East. There is also reflection of inequitable distribution of attention and resources to the northern region. The northern part of Uganda which is recovering from civil conflicts (other districts are still under insecurity) that has engulfed Uganda since the 70's is disadvantaged compared to the south in terms of urbanization, wealth and education (MoFEP, 1995, Barton Wamai 1994).

2.3. Current political system

The National Resistance Movement developed a decentralized political system called Resistance Councils (now called Local Councils). These councils are locally elected by the people and are on five levels. They are the representative bodies of the present government under President Yoweri Kaguta Museveni. These councils start from Local Councils five (LC V) at the district, down to LC IV which is at county level, to LC III, LC II and the last Village council which is LC I (about 30 to 150 households). There are various posts at each level such as LC member in charge of Health, finance, Defence, youth, secretary for women, etc. Each level is headed by a chairman. All citizens above 18 years constitute the village resistance council and are eligible to vote in local village local committee elections. At higher administrative levels like LC II to V, committees are elected from within membership of the committees directly reporting to them. At each level there has to be

a woman representative, though a woman can also stand for any other post on the committee. The Local councils are charged to identify local problems, find solutions and formulate development plans. Each district has an elected woman representative in the National Resistance Council (NRC or Parliament).

2.4. Health care system

Uganda's health care system comprises of the formal which is predominantly public but with a large private, informal sector that has developed in recent years. Uganda had one of the best health care delivery systems in African in the 1960s. The system had been set up by the colonial administration whose major objective was to keep an economically productive population healthy and enhance better rule in the country. The economy was good and drugs and other services were provided free of charge at government health facilities. Government health facilities were heavily attended at that time and there was limited private practice. However, the strong social environment, diminished with the internal civil strife and the economic turmoil that characterized the 1970s and 1980s. There was a breakdown in the economy due to political and social instability, fall in international commodity prices thus affecting the export earnings, global recession and the burden of the foreign debt. Social services including health services broke down. The working environment in the health sector became hostile and many doctors migrated to other countries for security and economic reasons. Drugs, equipment and other hospital facilities were became short in supply and the quality of health care drastically fell. At the same time an unregulated private sector mushroomed rapidly to fill the services gap created by the poor functioning government facilities.

Since 1986, the government has been trying various measures to build up health services in terms of personnel, facilities and mechanisms of management and control. The government felt it would no longer afford free services to the people as it was too expensive. It has tried to shift from centralized national health services which it inherited on independence to a decentralized autonomous district management. Some reform initiatives such as decentralization and cost-sharing were instituted. Health sector decentralization policies were implemented.

2.5. Health Research Status before ENHR was introduced in Uganda

Since the 1930's Makerere Medical school and Mulago teaching hospital have been the centre for medical research in the country. This was mostly clinical research and the centre became one of the best in medical research in tropical Africa. Despite all that there was no clear link between researchers and officials of Ministry of Health who are the policy makers.During the colonial era a number of research institutes existed in East Africa. In Uganda was the Virus Research Institute

(Entebbe) ant the Trypanosomiasis Research Organisation in Tororo. When the East African Countries (Uganda, Kenya, Tanzania) got independence in the early 60's a move was made to form the East African Community and the research institutes belonged to the community. The Arusha East African Medical Research council governed these institutes, still there was no direct link between the research Institutes and Ministry of Health. In 1977 the East African Community collapsed and the research institutes were given to their parent countries. In Uganda the research Institutes were placed under the Ministry of Health. Prior to the community breaking up, Uganda realised the need to coordinate research and established the National Research Council in 1970. It was housed in the Ministry of Planning and Economic Development. Priorities that were set were mostly in medicine on the burden of disease. In 1973 during Amin's regime the research unit on malnutrition of children was closed down when the Asians were expelled.

3.0. Community participation in Uganda: Historical perspective

Uganda has witnessed changes in community participation. Historically communities in Uganda have participated communally in a number of activities. Some were purely emergency-oriented organizations such s local burial assistance groups that provided material and psychosocial support to the bereaved family. Other groups were the rotating labour sharing group in agriculture - clearing,planting weeding and harvesting stages. Neighbours provides such labour. Historically community participation in Uganda can be traced in the 1950s when community development movements emerged. The British colonial government introduced such participation as a strategy of its administration especially for the veteran from war to find the villages better and secure support active participation of the citizens for their socio-economic progress. This was to work through mutual cooperation and self help organisation. In 1952 the first department of community development was created this marked the beginning of community participation in Uganda. This was done through adult literacy campaign and community development in infrastructure and community amenities (Neema 1994, Muzaale and Birungi,1997).

After Independence in 1962 there were community projects aimed at benefiting the entire community. Participation focussed on small communities at the local level with an attempt to mobilize people improve their surroundings. These were self help projects/activities (*Bulungi Bwansi)* in road construction, schools, social centres, water protection etc. They were not so much different from the pre independence strategies, both were government activities planned and implemented by central government, enforced sanctions through chiefs. These had negative consequences f community participation because the community did what they were expected to do e.g construction of latrine but in actual fact did not use such facilities. They refereed to such facilities as "government facilities"

During the Amin regime 1971-79, there were problems of voluntary community participation due to dictatorial rule of the military regime in power and the eroded community participation., Community based organization whether religious or otherwise went underground for fear of being mistaken as political opponents. Community participation was more coercive than voluntary. However, civil strive and turmoil of 1981-86 halted some of the community participation activities. Locally based organizations were regarded as potential threats to the regime and were therefore either co-opted or banned. The state positioned itself as a motor of development and provider of services, leaving no room for active participation of non-state institutions in the development process (Sembojja and Therlkdsen 1995, Birungi et.al 1998). During this regime it was more of coercive community participation that voluntary, and those who refused would be in some instances imprisoned.

After the fall of Idi Amin between 1980 and 1985 there was a lot of turmoil and the country experiences five regimes in such a short time. In a bid to revive community participation one of the regimes institution a policy of collectivization - Mayumba Kumi (ten cell/households). The system was for security checks, and also for distribution of the scarce essential commodities such as soap, sugar, salt etc. Only those who participated in Community work were given the essential commodities. Hence Amin's coercive participation was replaced with Obote's bribed community participation. Both participation were not stimulating a bottom up approach (Muzaale and Birungi, 1997).

Non Governmental organizations and community based organizations started emerging either by private individuals or under religious denominations. It was in 1980 when Uganda Community Based Health Care Association (UCHBCA) was formed jointly by Ministry of Health, Ministry of Local Government and NGOs concerned with Community Based Health Care (CBHC) and PHC with the assistance of UNICEF.The association realised that CBHC programmes should be both community based and community controlled for full community participation.

Under the current government - the National Resistance Movement (NRM), popular participation emerged and was from bottom grassroot to upwards in the administrative and political hierarchy. Since 1986, the government of Uganda embarked on people participating in the affairs of their community life. In Local council elections, people choose their own leader, they are mobilized and politicized to take charge of their own affairs, through a hierarchy of local council committees. The five hierchical councils govern the district and are democraticallay elected. People in the community are automatically members of the council and are entitled to participate in the decisions and planning at the grassroot. The local councils are mandated to carry to spearhead grassroot development.

It is under this NRM regime that decentralisation programme came into force. Uganda adopted a decentralisation strategy in 1993. Under this policy the district level became the main unit of operation for most government programs. One of the objectives of the policy is to bring political and administrative control of services to the point where they are actually delivered, thereby improving accountability and effectiveness and promoting people's feeling of ownership of programs and projects executed in their districts. When the local committees are empowered to be responsible of their affairs the decentralisation programme is expected to build structures that are responsive and accountable to the public and promote capacity building at local levels. With decentralization it is believed that it bring decision making closer to the people.

It was also at the beginning of this regime (1986) that the county started a comprehensive primary health care that drew together NGOs, health care providers and other agencies. The purpose was to revitalize primary health care focusing mainly on preventive, promotional and basic care initiated and owned by the communities. Seven years later the government adopted a local initiative, that aimed at making communities self reliant so that they can identify their own problems, identify the root causes of these problems, decide on the activities to overcome these problems, plan, organize and implement these activities, monitor and evaluate the activities and their effect on the health of the community, and know where to look for outside assistance when required (MOH 1993).

Uganda is also a signatory to the PHC where the community has to get involved in their health (CIH). PHC stipulates that communities have a right and duty to participate in decision-making concerning their health and the services provided, the people have the right and duty to participate individually and collectively in the planning and implementation of their health care (Alma Ata Declaration IV). Hence with such a rich context community participation in ENHR process would be facilitated with less hindrances.people would be willing to participate given this country culture of participation.

4.0. The process of introduction of ENHR in Uganda and community participation

In Uganda Essential National Health Research (ENHR) strategy was adopted in 1991. Since then a number of activities have taken place. The first ENHR workshop was held in the same year basically to understand the concept of ENHR. A number of stake holders participated in a three day workshop. The community got involved through the invited NGOs as they would talk on behalf of the community. At the end of the workshop one of the recommendation was to create a task force to consult widely and set up research priorities. The task force should be multi disciplinary and multisectoral. There was insistence that somebody from the community be included and this was a representative from the Uganda Community Based Health Care Association (UCBHCA). In that respect the community was involved. In the process of trying to identify priorities the Task force visited and consulted with:

i] Policy and decision makers

These included senior officials of the Ministry of Health and other relevant ministries e.g local government (PHC), Agriculture, Planning and Economic Development, and Education. Personal interviews were conducted with these officials. Explanation of the concept of ENHR was done by the adhoc committee and in turn the officials made suggestions on how their contribution would lead to an integrated approach to health research, how research findings would enable them make informed decisions in their policy formulation.

ii] Health researchers

Consultation with researchers about the current status of health research was done through a self administered questionnaire. Senior researchers were interviewed many of whom had attended the ENHR workshop. Data from the questionnaires revealed that about two-thirds of the research completed and ongoing was biomedical and only one third was community oriented. In addition most of the researchers were in favour of developing a national research agenda but gave lack of funds as a foreseen constraint. The committee also reviewed literature to find out the kinds of research that had been conducted over the past years.

iii] Communities

Four districts one from each region of Uganda were selected for consultation with communities, but due in insecurity in the norther region, only three district participated in the discussions on what they perceived to be their health problems. This was a participatory method in form of focus group discussions with the community. The three districts were Iganga, Mukono, Hoima. A two

day seminar was held in each district involving district planning committee members and the district health team. Some members of the planning committee were politicians representing rural communities. Among other things these seminars helped to select various communities that involved men and women of varying ages to be participants in the focus groups. The discussions revealed that unlike researchers whose priorities were based on disease burden, the community members had more holistic views on health problems. Their concerns included low family income, lack of markets for their produce, bad roads, harmful cultural practices and inadequate health facilities. Their specific health problems included Malaria, diarrhea and respiratory tract infections, AIDS TB skin disease and intestinal worms (Neufeld et.al 1997). This consultation with the communities in the districts provided a sense of how the ordinary people think about research and their health related problems. The report clearly indicated how involving the community at village or district level was important.

The outcome of the these consultations resulted into the development of mechanisms for research priority setting, which were followed by the development of a national ENHR plan for the period 1993-1995. This Plan was in line with the overall National Health Plan. The Plan was formally approved by the ministry of health (MOH) and the Uganda National Council of Science and Technology (UNCST) and launched in May 1993. To implement the plan , a small secretariat for ENHR was established within UNSCT, and an interdisciplinary ENHR coordinating committee was formed. However there were funds to implement the plan as the country was just recovering from economic crisis. The following year in February the ministry of health convened an international donors workshop to mobilize resources in support of the ENHR Three Year Plan. The results of the workshop were not very fruitful, finally the Carnage Corporation of New York provided funding to support some ENHR activities. The main achievement of this plan was that the ENHR strategy has been institutionalized and national health research priorities were discussed and agreed upon.

In 1997, a National ENHR Consultative Meeting reviewed the ENHR Plan for the period 1993-1997 and discussed a proposed plan for the period 1997-2001. This plan was drawn and launched and will be reviewed every one or two years. It supports the implementation of the National Health Investment Plan for the period 1997-2001

ENHR coordination in Uganda is done by a secretariat consisting of a coordinator, a research officer and a secretary. The secretariat in addition has a multi-disciplinary committee of six researchers who are actively engaged in ENHR implementation including capacity development activities.

4.1. Capacity Development

With support from COHRED, A Ugandan local team of researchers under the Coordinator of ENHR-Uganda, conducted a CD/ENHR study among organizations that are directly involved in research and those which are primarily funders and users of research.

The objectives of the study were:

Review Uganda's current Capacity to conduct, use and manage priority driven health research, use the results of the reviews to develop a capacity development plan as an integrate component of Uganda's new ENHR Plan, and finally contribute to an international exploration of CD/ENHR. A workshop was conduct to discuss and review recommendations and develop a plan of action. Among the recommendations was the development of a national health research data base to include a continuation of a project registry, an inventory of health research organization, funding agencies and a list of individual researchers. Strengthening ENHR at district level with focus on demonstration districts, establishment of a newsletter, and the formation of diseases specific research groups has been so far done.

4.2. District Involvement

After the Annual African networking meeting held in Tanzania in 1997 there was an expressed need to involve the districts in the overall process of ENHR. COHRED commissioned a small working group to collect, document, and analyse ongoing experiences wit ENHR at district level and identify key issues and problems involved and come up with strategies to deal with them. The national mechanism has carried out sensitization seminars to representatives of the district health teams from 30 out of the then 39 districts. Seven District medical Officers (DMOs) were given the skills to carry out health research, through training and development of relevant research proposals to tackle health problems of their districts

Later in January, 1999 after realizing the fact problems district were facing in the implementation of decentralisation the national ENHR coordinating team in Uganda embarked on an exercise to develop the capacity for health research at the district level as a tool for development. Two rural districts of Lira and Kamuli were finally selected and were visited by two members of the national ENHR Coordinating Unit. The two initially held a two-day discussion with various district authorities to introduce the concept of essential health research and its value as a tool for district development. Copies of the COHRED monograph on research priority setting were distributed to some members of the District Health Team. Subsequently, a larger meeting involving various stakeholders in the district was arranged to discuss district health problems, and to set research

priorities. The team had visited the districts to identify the district willingness, capacity to do and use reach. From the three district three, two were selected for trained to write their own proposals and do the research.

The selected districts identified research topics that were relevant, and proposals were written and funded. Topics included health financing for Lira and Malnutrition, record keeping for Kamuli district. So far they in the field during filed work, after the field work they will come back to Kampala for training on analysis of their data which will be dissemination to the districts and used for planning.

Another issue worthy mention is the establishment of Uganda national Health Research Organization (UNHRO). After the East African Community broke up, Tanzania and Kenya each created its own research institute e.g KEMRI in Kenya. Uganda could not set up one due to the civil strife and turmoil that characterized the situation that period. Hence UNHRO has been establish. It is hoped that it will take over the coordination of health research in Uganda.

Some of the conclusions were drawn from the process of implementing ENHR in Uganda is that as far as research capacity is concerned there are few researchers many of whom are young and inexperienced hence need some strengthening. Financial resources for funding research is insufficient implying that even if the researchers, community and policy markers set priorities some of them would be difficult to achieve financially. Inspite of such shortcomings, there is a great deal of interest in ENHR initiative in Uganda, researchers are cooperating to ensure its success. In addition the government has shown strong political will. (Owor and Okello 1997).

5.0. Community participation in Selected Research Projects

5.1. Profiles of the research projects:

a] Title of the Study:

Needs Assessment survey of persons with AIDS, Care Givers and Orphans in Mpererwe Community

b] Description of the study:

This was a community survey conducted in Mpererwe a peri-urban settings near Kampala city. The principle Investigator was a medical Doctor from Mulago Hospital, Dr. sam Luboga. The Study was conducted in 1996. The study was on the Needs Assessment survey of persons with AIDS, Care Givers and Orphans in Mpererwe Community. Earlier in the same area, in 1993, teachers and students of the Faculty of Medicine and community representatives conducted a baseline survey. In february 1994 the faculty and the students explained the results of the survey at a seminar organized in the community. The survey finding indicated that high morbidity could mainly be attributed to poor water supply and inadequate sanitation. The community was prepared to work with researchers and local policy makers to carry out research aimed at finding ways of improving the situation.

c] The Problem:

There was a problem of HIV/AIDS and its impact led to increase in orphans in the area, and care giver for people with AIDS did not have good knowledge on how to care for them. In addition the extended family systems's resources were inadequate to cater for the orphans, it could no longer cope with such problems.

d] Objectives of the study:

The main objective of the study was to assess needs of the AIDS patients, Orphans and Care-givers in Mpererwe community. Specifically the study was to assess the level of people's knowledge and attitude towards the AIDS scourge; to establish the number of AIDS patients and orphans in the community and assess the kind of support they need which can be sought from local volunteers and donors.

e] Methods:

Methods used included documents review, baseline community survey, focus group discussion with community leaders and group discussion with church congregation, and Key informant interviews.

f] Main Findings and Recommendations

HIV/AIDS awareness was high (attributed to government and NGOs campaigns) and some households (7.6%) had AIDS patients and some were not seeking health care due to lack of money. People in the community were supportive of AIDS patients and there was a large number of orphans (56% of households reported living with orphans). Major needs of AIDS patients and orphans included: medical treatment, food, clothing and beddings, school fees (for orphans of school going age). Caregivers expressed a need for education about patient care and protective measures to avoid contracting the disease while nursing AIDS patient. There were a number of recommendations from the study, one of which is *" Given the patients' orphans' and care-givers' needs in the study area, there is need to train and facilitate grassroot people about feasible income generating activities so that families can generate incomes for their needs instead of relying on donor support most of the time... strengthen extended family system".*

g] Process of community participation

The principle Investigator Dr. Luboga of Mulago Hospital had been working with Mpererwe community for some time. In the study area HIV/AIDS was a problem with negative consequences such as a growing number of orphans. Though the knowledge of HIV/AIDS was high, they lacked care giving methods and needs were enormous. Hence the principle investigator in conjunction with two researches wrote a proposal and were ready to go to the field, they first called for volunteers to participate in data collection. These were members of Mpererwe community. The PI and his research team called for a meeting with the community leaders and asked them to identify young people with minimum education (not less than senior 4). In addition during the meeting with community leaders the Researchers explained the objectives of the project. The announcement was also made in church, and about twenty community members as volunteers were recruited to help in data collection. There were trained in research methods, understanding the questions and how to create rapport in the community. They were trained by researchers from Child Health and Development Centre-Mulago. Other than passing through the church they used the existing Local council (LC) system who are the local leaders.These leaders gave the researchers a go ahead and were to prepare lunch for the research team. Money was provided by the PI for food but it was not enough so the community participated by providing some staple foods such as Bananas. The

community members were the ones to decide what food should be cooking and prepared it. In addition the local council leaders provided guides from the community to take the researchers around the homesteads. The questionnaire was discussed with the community leaders some of them became respondents and in away they influenced the questioning if they felt it was culturally sensitive. The Questions that were not good for their community were either re-phrased or omitted. For instance the question on income was difficult to b asked and the local leaders indicated that if they asked on expenditure they would get better response because people believe if they tell the actual income they will not get assistance.

The researchers definition of community was" geographical i.e people living around the catchment area of St Stephen Hospital in Mpererwe. The radius is about 10 Kilometres. The parishes included Kanyanya, Kawempe II, Komamboga. It also included those people in that areas that share same problem or that are affected by what happens in the vicinity. The Research Team disseminated the information to the community in various Fora: Local Council meetings, church. There is yet a big community dissemination in the offing. Results from the study was to help them write project proposals to help community members in income generation.

Bugiri District

a] Title of the Study:

Community Participation in Tsetse Control (Phase I)

Integration of community participation in tsetse control into PHC (Phase II)

b] Description of the study:

The project was in two phases 1st phase was from 1988-91. The second phase was in 1993 and ended in 1997. The aim of the project was to control tsetse flies and they used a Primary Health Care approach - of involving the community. The Principle Investigator had earlier experience with control of Tsetse flies and he is an entomologist. He realised that it was good and cheaper to involve the community and integrate with already existing government efforts and work as partners.

c] The Problem:

There was a problem of Tsetse flies in the area and people and animals were getting sick. The government could not afford the expense of controlling the tsetse flies. The traps were expensive and would last for only 9 months.

d] Objectives of the study:

To control tsetse fly infestation in the area through community participation.

e] Methods: More of entomology but people were trained to trap and identify the flies.

f] Process of community participation

The community was approached through the local council officials. Some members of the community were selected to participated in the training and sensitization on how to make traps, how to trap the flies. Existing theatre groups were used also to sensitize the communities about the need for them to come up to join hands and fight the Tsetse flies. The community was also asked to contribute money to materials for the traps. The district Health Educator, Health inspector, Vector control medical entomologist, youth officer, district children welfare officer were also participating to sensitize the community. People learnt to make traps and gained ownership of the project. It was very good because people would even bring the tsetse flies they caught. Local leaders also participated in painting and impregnating trees. Women's clubs also got involved e.g Tugyeyoku Tubone Church's club, and another church's club in Buwunga. They would go to sub-counties and stage plays on tsetse, composed songs on Tsetse fly control.The community was

involved as I have told you and also they could pay money to teach them how to make traps. Local leaders and people chose mobilisers and mobilized people. LCII provided money for painting the traps. Some just picked interest. Local councils III were to solicit funds then to LCII and LCI for mobilization to identify villagers and trees to be painted and then mobilization of communities.Representatives were chosen during monthly meetings. The researchers would make suggestions on work to be done and suggest who to use. To maintain interest of the community, when the flies reduced, they tried to integrate people's economic activities with tsetse control.

6.0. Synthesis and findings

1] Defining and Describing Community in the Uganda ENHR process

Examining Uganda's data on definitions and meanings of community, there emerged various meanings depending on who was defining it. Most of the people interviewed understood it in terms of the geographical sense and the shared experiences and togetherness. In the process of implementing ENHR in Uganda, the researchers and the Task force understood community as a people usually defined by location (geographically and administratively) who have a number of things in common such as shared experience, functions, problems, and who may share common property (land, water, firewood etc), and other social services in their vicinity. Geographically it meant a location where people live. The size of the community varies and is at different levels. For instance it can mean people in certain households, in a village/Local Council I, parish/ Local council II , sub-county/Local Council III, county/Local Council IV, district/Local Council V, and region. These geographical communities are also administrative communities. In these communities there is interaction and in emergency or crisis situations these people help each other within their means. The geographical definitions relating to community was also echoed by the Mpererwe researchers and that community was all those people who were living in the catchment area of St. Stephen hospital - a radius of 10 Km. It included villages of Kanyanya, Komamboga, Kawempe II, and Mpererwe. In Bugiri study the community was defined as those people living in Bukholi county which is the current Bugiri district.

> *All those people who live there, those who live in that area - a defined area (Researcher, Bugiri)*

> *A community are people living together in a locality (DHE, Bugiri)*

> *A community are people living in an area, they have a church, a health facility and are living around such facilities and have access (KI- Mpererewe)*

Another definition by the researchers relate community with particular/own identity and togetherness. It implies that the community has leadership and can be reached if need be by outsiders who do not belong to that community.

> *Those people who have their own identity of some sort. It may be a village or sub-county but the people have some kind of leadership, and can be reached, they can be either in urban or rural. There is some kind of togetherness (Task*

Force Member).

One of the Researchers described community as a **Rubie Cube**, comprising of heterogenous members. Membership differs for instance by age, religion, ethnicity, gender, education levels, socio-economic status, health status etc. A person can change from one characteristic/state to another except for gender. Within a community there are there are some sub-communities. The definition of community members can change depending on who is being targeted. For instance in the Mpererwe community as a whole, the researchers did a needs assessment of particular sub groups of People with AIDS, their caretakers and the orphans. Yet in the same community there were people who were not having AIDS, or children who were not orphans.

Community was also defined as those people who are members of an organization. For instance they cited members of religious groups like St Augustine Community, the moslem community, the born-again community, etc.

NGOs were seen as representing or speaking for the community during the initial stages in the implementation of ENHR. Community was also used to mean NGO as representing the people that is why in the first Advocacy meeting launching ENHR they invited the chairman of Uganda Community Based Association as speaking for the community. Another aspect of the community is the district being invited some of whom were representing the community.

> *We invited NGOs whom we thought spoke for the community (Task Force member)*

Also community meant the villagers who participated in the focus group discussions during the priority identification phase of ENHR process.

Another meaning of community was some people out there, the grassroot, the masses, who are disadvantaged in terms of for instance accessibility services or resources.

> *When I hear the word community it means us here who have problems, we are sick, not enough medicine, and sometimes we are helpless (community member, Bugiri)*

Community also implied shared background. For instance by ethnicity, and those exposed to a particular hazard, or with a similar problem. For instance in Bugiri because of Tsetse fly infections in the area people suffered a lot from sleeping sickness and hence this was a community of people with Tsetse flies problem. In Mpererwe they shared similar problems, used the same community facilities such as St Stephen Hospital and Mpererwe Church of Uganda, and the local markets and schools. According to the principle investigator of Mpererewe study, they defined community in terms of a catchment area of St Stephen Hospital. The catchment had a radius of 10 Km. It included all villages within that catchment radius.

The local members defined community in terms of themselves, village members or parish members, under a one local council. To them proximity or neighborliness was key to the meaning of community. It was more the people they know that would constitute a community. Typical quotes included:

> *We are the people, we leave here in our village, we have leaders, and our local family, clan leaders. We know ourselves, we are the people who live here, Abatuuze. (KI - Mpererwe)*

The above quote implies that there seems to be not direct meaning of community other than referring to phrases like: people of such and such area *(abantu be gyindi, abantu bekyalo*), women of such and such area.

Hence, it all depends on who is defining community. The researchers come with their already defined meaning of community. It could be one of the above or all of the above definitions. The outsiders may want to lump people as a community yet people may feel not a sense of togetherness to constitute a community. There are also sub-communities with in a community, depending on whom one is targeting or talking about. In the ENHR projects the definition of community depended on the type and nature of the project; the problem to be investigated, the goals and the target population. It was both geographical and also people targeted for an intervention.

2] Describing and defining community participation in the Uganda ENHR process

In instituting ENHR in Uganda community participation was and is important. The community is one of the three major stakeholders and involvement of community is an important part of the ENHR strategy. Usually the research carried out as part of ENHR meant that the community had to get involved. Like how community has different means depending on who is defining it, so is participation. Data from Uganda suggests that community participation refers to some involvement of the community in some activities of the research process. Community may participate at different level and in different activities depending on the research project. They may be consulted, informed, and get involved in the planning process, get sensitized or trained, help in mobilizing, act as data collectors and help in dissemination and intervention phase. It is not all members of the community who participate, but once some members participate, it fits to be called community participation. This will be highlighted in the discussion below.

In Uganda, the ENHR Task Force involved the community at various levels and different capacities when the ENHR was being set up in Uganda. The first ENHR workshop that was held was to understand the concept of ENHR A number of stake holders participated including the community represented by NGOs. Specifically Uganda Community Based Health Care Association (UCBHCA) represented the community. During the identification of priorities the Task force visited and consulted policy makers, health researchers, and communities. The communities were from the four regions of Uganda through participatory focus group discussions. The community was also represented during the ENHR consultative meeting that was convened to review ENHR Plan for the period 1993-97 and discussed proposed plan for 1997-2001. The District Health Teams included community representatives.

In both research project there were activities/elements of ENHR where the community participated. There were different kinds and levels of participation. The Researchers indicated that they identified a problem being citizens of the country and seeing people suffer, there after they wrote proposal and identified the area of study where the problem is common. The community also when approached indicated it was a problem but they had no means to investigate it. Approaching the community was the next stage. The community was approached through the local leaders (LCs). Permission, consent, acceptance from the local leaders was sought to work in the community. The researchers indicated a need for the community to participate. What is important is to understand how and to what extent the community participated in the two research projects. With the Sleeping sickness project in Bugiri, people from the community through the Local Council structures were approached and invited to come and participate in the study. They got trained and started actively participating in the project.

When asked how the research in Bugiri wanted the community to fully participate he answered like this: **Unlike in government projects where only the community was to protect the traps so that they are not stolen or burnt, or just slash around, in his project the community had to make their own traps with their own resources, do the trapping, catch and identify the flies, and all flies collected would be brought to him - the entomologist (principle Investigator). They were also supposed to service their traps.**

Criteria for selection of the community participants in both project was based on those who had some level of education and were willing to participate. People were trained who in turn went to train others. Community meetings were conducted, and focus groups to sensitize and mobilise the people in Bugiri. After the researchers interested some community members, the selected their own leaders/chairpersons.

> *When Mr. Okoth came he selected some few people of our group who he took for training these came back and trained us so we in turn went to train other people in our area did this in several parishes. We would set traps and tsetse flies had reduced even to a noticeable level (Traditional Birth attendant, Bugiri).*
>
> *I was selected because I was the chairperson of the church group so the members said let the chairperson go (KI Bugiri)*
>
> *I was LC I see for people so we LCs were taken for training/sensitization in Namasere sub-county headquarters.(KI, Bugiri)*
>
> *People who were selected were knowledgeable or they knew them like Mr. Otebba. We local people were never involved they were just elected from up- from other places, we would just see them come and set traps.Working together/combine efforts with health workers (Group participant).*
>
> *When your education level is higher than others then you are selected (KI, Mpererwe)*
>
> *Researchers would identify people who were good mobilizers as members(KI. Bugiri)*
>
> *If you are clean at home they would come and teach you and then make you join the group (KI, Bugiri).*

One of the researchers in Bugiri mentions how they selected people and groups to participate.

> *In all places we knew we had some drama groups but we chose the best performing ones, sensitized them to perform on what we sensitized them. Then we selected elders (opinion leaders) and taught them who also went to village to educate others. At some stage we wanted responsible people e.g priests teachers and we worked with them. When you are trying to educate somebody try to use all tactics so that she/he understands you. You have to use better language and words to convince them. It has to be a proper approach. Persist in visiting them to ensure that people are reminded to prioritize the problem.*

Participation according to the community meant:being consulted, getting involved in some of the research activities, being part of the respondents, and also knowing the outcome and benefitting from the research. Others mentioned some kind of collaboration where they work together and combine efforts with health workers/researcher.

Another meaning was identifying own problems and people getting involved in planning decision/being consulted.

> *At community level participation means people identify their own problems and set feasible solutions and take action (DHE, Bugiri)*

> *People come together and make a decision and get empowered and own the process, and should not be coerced or forced to participate (KI, Bugiri)*

Other meanings were: Getting practically and actively involved in the project activities.

> *Participation the project meant that we practically getting involved in activities to prevent Tsetse flies from biting us to cause us get the disease*

> *Since I know that there is a disease which kills us human beings. I need to participate fully by involving practically fighting of tsetse flies.*

Other members of the community understood participation to mean providing information/labour/materials when requested and gaining ownership of the project

> *Some people were taken for training in techniques who were to teach local people on how to make traps.People learn to make traps and gained ownership*

of project It was very food because people would even bring Tsetse flies they caught (DHI, Bugiri)

At first people had to be convinced to participate and through sensitization people had to know and identify their problems, they realized that nobody could do it for them they took action by making traps., painting trees and impregnating them (DHE, Bugiri)

Others understood community participation to mean that they themselves have to take active involvement in the activity to rid themselves of the problem with minimal assistance from outside.

I understand participation as that we ourselves have to take active involvement in activities to get rid of the problems with minimal assistance from outside (KI, Bugiri)

Community can participate through the existing groups. In Bugiri the researchers worked with the existing groups.

Since we were already in a group and used to hold meetings working together started their sensitization program. They selected some of us for training. We had a problem of disease and some men came to train and sensitize us about tsetse fly control by clearing bushes, setting traps, and untrapping, we would set traps, catch flies after making traps. After sometime they came and asked us to stage a play we got problems because we used to provide our own food and transport, the sub-county had promised to assist us but failed us so we used to go un aided several times (Walugoma church group member).

Channels of participation.

Channels of participation used was through existing political and administrative structures. For instance in Bugiri they used the Local Councils to mobilize the people. In Mperewe in addition to the local councils they used church gathering to call/announce for participation. People were invited to participate as volunteers. They were sensitized and trained on how to collect the kind of data the researchers wanted. In the case of Bugiri those who were initially trained had to train other members of the community.

If they are the first to be sensitized. They learn new ideas and bring in area to teach others (Researcher, Bugiri)

The Mpererwe community had volunteers who participated in data collection during the needs assessment study. This community participated in designing and/or redesigning the questionnaire. Some questions that seemed to be sensitive were either rephrased or omitted.

3] Assessing community participation in the Uganda ENHR process

In assessing community participation in ENHR there is need to understand the process and outcome of participation at the national and project level. At the national level the during the initial launching meeting attended with the researchers, policy makers and representatives of the community. This initial process of promotion and advocacy might not have involved the community so much except for the NGOS that were invited. At a later stage the district officials including community members were met at the district and were involved in priority setting for research. This was a good way to make the communities set their priorities, and identify their needs. Training district personnel and let them prioritise their research needs was important, and this will create capacity at that level to carry out ENHR.

At project level, in both projects the problems affecting the community was eminent except that the community members had not organized themselves to do something about it. They lacked funds and may be people with research skills to identify the problems and carry out the study.

For instance sleeping sickness was a problem causing morbidity and mortality in the community, and there was the problems of orphans and people with HIV/AIDS. The researchers spearheaded the studies consulting the community leaders and members for their co-operation. In the Mpererwe study local people as volunteers were used as interviewers and guides. Consultation was also in both studies with the local leaders

Entering the community and soliciting participation

In both projects the local leadership structure of Local Councils were used to enter the community and solicit permission and participation. In addition Mpererwe study used the church calling for volunteers to act as interviewers. The leaders are representative as in Uganda each adult belongs to a local council. Working through existing Community based groups such as drama groups, and women groups was also beneficial since they are already mobilized and organized.

Contributions of community to the project

In both projects community contributed monetary and physical labour. In Bugiri the people has to pay some money for the traps, though some failed to pay. In Mperewe the community participated in provision of additional food and preparation of lunch for the twenty interviewers during data collection phase.

Involvement in decision making

To a certain extent some members of the community were involved at some stage identification of their needs and implementation. But this was a bit limited. It was limited the local council officials. Mpererwe study community helped in the design of the questionnaire. Limited participation can happen especially when community members are not equipped with some knowledge and skills to participate in research. In some instances a more limited forms of participation is inevitable and even preferred. It is important to understand whether people really are interested and want to participate. Some people may not wish to be involved, others still want to know more about the project and build confidence. They need to be full informed about the research and the role they will take if they are to participate. It is only then that they can make an informed choice either to participate or not.

Full control of the process from design through implementation to evaluation is important but realistically it might be difficult to achieve. The community might participate at certain stages of the research more than other stages. In addition when we talk of community participation it does not necessarily mean all members of the community, but rather some member are selected according to various criteria to participate, others are seconded by the community themselves. This happened in both studies. The community participates but with varying breadth and depth, and at different stages/phases of the research process. The type of research project sometimes dictates when the community should called to participate, and what they should participate in.

Dissemination

One of the weakness in the process of community participation ENHR in Uganda is to do with dissemination of results. Very rare were the results disseminated as quickly as possible to the community which is eager waiting for the outcome. In the Mperewe study the researchers reported some preliminary findings at a church gathering and to some Local Council officials but are yet to plan for a major community dissemination. The use of a church gathering might leave out community members who do not go to the same church. In Bugiri the community members were mentioning that the results were not disseminated to them. Typical quote:

> *They used to write but not tell us, they used to ask us and we would give them reports and everything about our condition and they would write and go but what came out was that health workers were brought nearer to us (FGD member, Bugiri).*
>
> *No results told to us those people came for tsetse flies and took them and got money and we who trapped them got nothing (FGD member Bugiri).*

Constraints to community participation

Some of the constraints to participation that were eminent in the ENHR process included community fatigue especially in areas which have been over researched. For instance in Mpererwe earlier some orphans had been enumerated by an organisation and nothing beneficial came out of that. so they were hesitant to get involved again. Some community members were ignorant of the benefits of participation and never wanted to be bothered. Others were problems to do with renumeration. Some participants never wanted to work for free.

> *We had a problem that community was difficult to mobilize. They expected free things from government and that government should do everything for them. People we were working with wanted a lot of allowance, they would refer to other projects which were giving a lot of allowance (researcher).*
>
> *People want free things so when they were asked to contribute they refused (LC official)*
>
> *We used to get a lot of problems we go to Bugiri when called, no lunch, those people would fail to come wasting our time sometimes they would call us and we refuse to go (community participant)*
>
> *We are poor, we lack money to buy cloths, lack transport to mobilize (participant)*
>
> *Community participation has not been easy because of allowance syndrome. Many programmes have been giving big allowances for all services leading to problem of convincing somebody that it is their problem so they need to participate without getting allowances but some communities have responded positively (Researcher)*

Related to renumeration as a constraint to participation is the issue of the community participating as volunteers. If it is too much voluntarism it breeds non-compliance among some community participants. One of the reason is because of community fatigue, some areas have been over researched and they feel there has not been any benefit accruing to their participation in previous researches so they feel it is a waste of their time. In communities where people are poor even not affording a meal, voluntarism might be difficult as people will expect something in return for their participation.

> *People who participated need some support e.g Theatre groups, loose morale because of too much voluntarism and use of their own resources (KI, Bugiri).*
>
> *They themselves to participate in riding themselves of tsetse. But the problem of contribution was always echoed they were saying that they do not have money and that mobilizers needed motivation (DHE, Bugiri)*

In the Bugiri project some people participated partially hence echoing that there should be limits to voluntarism. The participants might spend a lot of time in the research work at the expense of their daily work where they earn income, and if they are not compensated somehow they might loose the interest.

Political interference was mentioned by the Bugiri group as one of the constraints to participation.Some leaders interfere with the research process and this is barrier to participation.

The community want the immediate benefits yet some of the benefits in most researches may take some time to mature. This is the case with the Mpererwe study.

Another constraint to participation is resources to include as many community participant as possible. Even if one desired it financially it is difficult to be achieved.

Gender was not considered in both projects in community participation. Women were mostly left out yet they are the primary health care givers at family and household level.

Success in enhancing community participation

In both areas there were some shared concerns by community, and this was important to make the people agree to participate. In both projects the participants were called volunteers and were not paid or if they were, it was a token. They also contributed towards the success of the project. The community was to participate by buying materials, making traps, trapping tsetse flies, and checking daily. The Tsetse flies were fought by trapping using traps, buying paint and painting trees then impregnating them with insecticide. The community were supposed to clear bushes near homesteads and expected to keep on trapping and slashing if any case occurred to report to nearest health unit for check-up. They were happy about their participation. They were seeing the results of their participation, flies reduced, diseases reduced and they were happy.

Involvement of the community in the studies set a framework for future community participation in those areas. The communities were empowered to be part of the process.

Process of involvement was adequate as the researchers followed the normal channel of entering the community. Passing through the local leadership structures was important, as it gave the community members a go ahead to participate. The leaders represent the community.

The community when asked indicated that they benefitted a lot in participating in the study. Some of the benefits mentioned include: Learning knew skills and being sensitized on how to make and trap Tsetse flies, there was reduction in Tsetse flies and sleeping sickness. People were trained for instance on data collection techniques.

> *I have knowledge about causes, prevention methods, treatment and where to seek treatment (Focus Group participant, Bugiri).*

> *I have learnt that this approach of the community members participating is better because initially it was the government setting traps but now and people were not supposed to touch them (Focus Group Participant, Bugiri).*

Commitment of people especially the project leaders and the community leaders.

If it is a health project there is need for active participation of other health workers, working in the community e.g Health educators, and active involvement of other stakeholders

The communities want a say in matters that affect them.It is only when the community is fully participating in research project and come up with answers to their identified problem that the intervention made will be their own - feel the ownership. They will in addition of owning the process and outcome also defend it.

7. Preliminary Conclusions and recommendations

Conclusions

Conclusions that we have drawn from this study include the following:

. Definitions and meanings of community depended on who was defining it and who was is being targeted. Categories of definitions that emerged:

  Geographical location (Village, sub-county, county, district, region)

  Shared experiences and togetherness.

  Rubie Cube, comprising of heterogenous members,

  NGOs representing the community

  Grassroot, the masses, who are disadvantaged in terms of for instance accessibility services or resources.

. Community participation refers to some involvement of the community in some activities of the research process at different stages

. Participation according to the community meant:being consulted, getting involved in some of the research activities, being part of the respondents, and also knowing the outcome and benefitting from the research.

. Other members of the community understood participation to mean providing information/labour/materials when requested and gaining ownership of the project

. Others understood community participation to mean that they themselves have to take active involvement in the activity to rid themselves of the problem with minimal assistance from

outside.

. Criteria for selection of the community participants was through local council meeting, announcing during church service: Those selected: had some level of education and were willing to participate. Existing groups were selected to participate

. Channels of participation used was through existing political and administrative structures. Local leadership structure of Local Councils were used to enter the community and solicit permission and participation.

. Working through existing Community based groups such as drama groups, and women groups was also beneficial since they are already mobilized and organized.

. Community contributed monetary and physical labour.

. Limited forms of participation is sometimes inevitable.

. Dissemination of results was still a problem.

Constraints to community participation

. community fatigue especially in areas which have been over researched.

. Renumeration and motivation

. Too much voluntarism it breeds non-compliance among some community participants.

. No been any benefit accruing to their participation in previous researches so they feel it is a waste of their time.

. Political interference was mentioned by the Bugiri group as one of the constraints to participation.Some leaders interfere with the research process and this is barrier to participation.

. The community want the immediate benefits yet some of the benefits in most researches may take some time to mature.

. No resources to include as many community participant as possible.

. Gender was not considered in both projects in community participation. Women were mostly left out yet they are the primary health care givers at family and household level.

. Short duration of study

Success in enhancing community participation

. Integrating people's daily activities with research and also some component of Income generating activity where possible.

. Involvement of the community in the studies set a framework for future community participation in those areas. The communities were empowered to be part of the process.

. Use of existing political and administrative structures is important as it gave the community members a go ahead to participate if the leaders represent the community.

. Some of the benefits mentioned include: Learning knew skills and being sensitized on how to make and trap Tsetse flies, there was reduction in Tsetse flies and sleeping sickness. People were trained for instance on data collection techniques.

. Commitment of people especially the project leaders and the community leaders.

. Involvement of other of other stakeholders (networking) to avoid duplication.

. Duration of study is important for effective community participation. If the duration of study is short by the time the community starts to participate like the case Bugiri, the project is almost ending.

Political good will is crucial in community participation. If the politicians are behind such ventures, the people will participate once they see their leaders in the forefront.

Communities want a say in matters that affect them.It is only when the community is fully participating in research project and come up with answers to their identified problem that the intervention made will be their own - feel the ownership. They will in addition of owning the process and outcome also defend it.

Recommendations

. Duration of study should provide enough time for the community to participate.

. Discuss with the community at the onset, let them participate in the questions to be asked that are sensitive to the community, and subsequent phases. The community should not only participate to receive you and give permission and provide guides but rather to be co-interviewers

. The results of the study should be disseminated to the community in the shortest time and it a manner they understand. They should be part of the dissemination process - participate in dissemination.

. Research proposals should have a component on how the community will be involved to participate

. Some facilitation where needed is important to avoid non-compliance due to too much voluntarism.

. Communities need to by more sensitized on the value of ENHR. This also includes the local leaders.

. Gender concerns should be incorporated in the research process to allow participation of the disadvantaged gender.