

# **DRAFT REPORT**

## **Community Participation in Essential National Health Research (ENHR) Process: Bangladesh Experience**

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**SECTION ONE**

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## **LIST OF ABBREVIATIONS**

BRAC	:	Bangladesh Rural Advancement Committee
COHRED	:	Commission on Health Research for Development
ENHR	:	Essential National Health Research
ENHR,B	:	Essential National Health Research,Bangladesh
NGO	:	Non-Government Organization
PIACT	:	Program for the Introduction and Adaptation of Contraceptive Technology

# INTRODUCTION

## 1.1. Background

The Commission on Health Research for Development (COHRED), an independent international initiative, was established in 1987 consisting of 12 members with great diversity offering broad experience in the field of health and development. The initiative was urged upon by the leaders from developing and industrialized countries. The Commission was formed in the belief that research activity and research capacity strengthening would play a significant role in advancing the health status of people in developing countries(1). The Commission was entrusted with the responsibility to make proposals for filling in gaps or otherwise promoting research in areas where this was urgently needed. It was also expected that the Commission would take measures to strengthen the capacity of developing nations to conduct health research and apply the results.

The Members of the Commission visited numerous countries and conducted hundreds of interviews, meetings and workshops involving community leaders, outstanding researchers, policy-makers and program managers. Based on these, the Commission recommended that each country should identify and prioritize its own health problems and design accordingly health policy and set programs suitable to its own circumstances. The policy and programs would thus concentrate its resources on the most important health problems, make use of the existing health knowledge and technologies, and yet pursue of an imaginative and experimental approach continually seeking to achieve greater health impact. All these would require enhancing essential health research capacity within each country. This research activities required in this area were termed by the Commission as Essential National Health Research (ENHR).

In fact, ENHR has been conceived as a process of determining national or sub-national health research priorities through a dialogue amongst three groups of equal importance in a cooperative relationship: decision-makers, researchers, and the community. This dialogue has to contain equity as its basic principle and where the principle is not equity, the activity is not ENHR. ENHR promotes National Research for Development, and in that sense it is a research strategy(2).

ENHR strategy includes seven elements: promotion and advocacy, ENHR mechanism, priority setting, capacity building and strengthening, networking, financing, and evaluation. Community participation is considered critically important in at some of these elements.

Despite the importance attributed to it, there is little systematic knowledge of how community participation actually functions, or could function in ENHR. Therefore, COHRED called for a study to examine how

community participation has been defined, understood and practised in countries trying to implement ENHR. This is a five-country study: Bangladesh, Guinea, Philippines, Trinidad and Uganda.

The focus of the study will be on community participation in several elements of ENHR (promotion and advocacy, priority setting, networking, financing and evaluations etc.). The goal is to examine possibilities, identify problems, and find fruitful ways of ensuring community participation in ENHR.

## **1.2. Objectives**

The specific objectives of the study are:

- i. To review how community participation has been understood, viewed and valued in health research at the policy level and by different segments of people such as health professionals and civil society and development partners in the context of Bangladesh.
- ii. To review ENHR process on the level of community participation in different elements of ENHR such as promotion and advocacy, priority setting and networking.
- iii. To document specific examples of community involvement in health research in general and in ENHR studies in particular to show modalities worked out for community participation and to extract lessons learned in community participation in health research with a focus on ENHR.

## **1.3. Outcome**

The study is expected to yield the following as outcome:

- i. A monograph containing ENHR process involving community participation, and empirical case studies of community participation in health research, especially in the context of ENHR;

- ii. A framework of community involvement in ENHR; and
- iii. Strategies for improved community involvement in different elements of ENHR.



## **SECTION TWO**

### **METHODOLOGY**

#### **2.1. Defining Community/Community Participation in the Context of ENHR Bangladesh**

The basic principle of ENHR, as stated earlier, is that it involves a partnership among three categories of actors: policy-makers, researchers and communities(3). Question arises as to who belong to this third group. In fact, in this study we do not try to define "community" or "community participation" in the abstract. Rather, we would examine how "community participation" is understood in relation to specific activities of ENHR in Bangladesh (hereafter called ENHR,B).

Community participation in health was a fundamental ideal in the Alma Ata Declaration of 1978. Although this Declaration did not include an explicit definition of community, an implicit definition can be derived from injunctions contained it. Community was treated as a locality-bound aggregation of people who share economic, socio-cultural and political characteristics, as well as problems and needs. A community was assumed to be a coherent unit, whose members would cooperate for shared purposes, for example expressing their health needs and planning services(4,5). The Declaration also indicated that communities could be regarded as sub-units of a country, a notion developed in the Ottawa Charter on Health Promotion(6), implying a hierarchy of individual, family, community and country.

Shared geographical location is an important element in some definitions of community. Several authors incorporated the notion of shared needs as part of their definition, thus preempting a debate about whether members of a community do actually share these. Das suggested that the notion of "community" could be interpreted as a similar group of people, for example, by health personnel, or as "at risk" group(7). Adams argued that "community" should be defined "geographically" or as a group having shared interest e.g. a street, estate, women's groups, etc. (8). Midgely specified shared "interests", without reference to either needs or location(9).

This brief review of definitions of "community" reveals that there is a lack of specificity and agreement about what the "community" actually is, whose participation is regarded as so essential. Many of the definitions are conflicting and suggest that what one person regards as a "community" another would not. Attempting to reconcile all the definitions available in the literatures in health, one is likely to run into difficulties(10).

However, in line of the definitions of "community" provided by Das(7), Adams(8) and Midgey(9), community should be viewed according to the nature of activities to be performed in a population. For example, in promoting a drug in a country medical practitioners in the country should be a target group and in this respect all the medical practitioners in the country could be termed as a "community".

**From the above perspectives, it can be argued that "community participation" in ENHR,B be viewed as the participation of those population groups who are relevant to be involved in implementing the different components/activities of ENHR,B.**

For example:

- a) The first element of the ENHR strategy "promotion and advocacy", has to consider "the people at large" to be sensitized about the needs of essential national health research.
- b) ENHR mechanisms would consider representatives of public interests and concerns, such as representatives from relevant government and non-government institutions, national health/population forums, women's forums and other concerned groups of civil society.
- c) In priority setting, "people in general" should be consulted.
- d) Networking involves dissemination of research results to policy-makers, program-managers, researchers and the public.

## **2.2. Procedures of Gathering Study Information**

To achieve the study objectives, the following steps were taken:

### **i) Review of Relevant Documents:**

- The review exercise covered the whole process of ENHR initiative in Bangladesh with particular focus on the structure of Working Group of ENHR, documents on workshops/seminars, process of priority setting of ENHR, process of implementation of research projects and the dissemination process of study findings.

**ii) Discussions were held with:**

- civil societies such as community based NGOs and women activist groups; and
- ENHR Working Group Members

**iii) Obtaining Opinion from the Stakeholders of Health Research:**

Included in this were:

- policy makers/program managers
- representatives of women's forums
- social scientists
- development partners
- ENHR Working Group Members

**iv) Case study of community participation in health development**

## SECTION THREE

### COMMUNITY PARTICIPATION IN ENHR,B

#### 3.1. Community Participation In The Process Of Promotion And Advocacy Of ENHR,B

It was mentioned earlier that COHRED, an independent international initiative, was established in late 1987 with 12 members (called Commissioners) from developing and industrialized countries including Bangladesh. The Commission's mandate was to survey health needs and research activities worldwide, to identify strengths and weaknesses, to promote needed changes, and to recommend means for continuing assessment and promotion of research on health problems of developing countries(1).

Mr. Fazle Hasan Abed, founder and Executive Director of Bangladesh Rural Advancement Committee (BRAC) was a member of the Commission. As a part of activities of the Commission, a national level workshop on ENHR was organized in Bangladesh by BRAC in collaboration with COHRED in June 1989. The purpose of the workshop was to bring into focus the strengths and weaknesses of health research in Bangladesh and to promote health research. The workshop was attended by 43 participants and it can be seen from below that majority (56%) of the participants were from various segments of the civil society such as Women's Forums, NGOs, Universities and autonomous bodies.

1.	NGOs/Private Organizations/Forums/Associations	:	10
2.	Academicians: Universities (Autonomous Organizations)	:	3
3.	Academicians: Government Institutions (Teachers, medical colleges and medical research institutions)	:	9
4.	Autonomous Research/Organizations	:	4
5.	Policy makers/program managers	:	7
6.	International NGOs	:	7
7.	Development partners	:	3
<b>Total:</b>			<b>43</b>

[Participants (4) from abroad have been excluded]

The need for ENHR was stressed in the workshop. The workshop concluded that mechanisms were seriously needed to:

1. Create an awareness of the importance of health information and research among the **community people at large**, the media, health professionals and policy makers.
2. Encourage changes in the medical curriculum to make it more problem-based and **community oriented**.

A follow-up workshop was held in January 1990. The workshop was attended by 23 participants. They were largely from NGOs (70%) and the remaining were from academic and research institutions.

Many of the participants observed that planners did not see the value of research. NGOs were seen as having an important role in strengthening government planning in health. The workshop came out with recommendations to introduce a Research Award Scheme to promote research among the **young researchers and students community**. A nine-member "Working Group" was formed for promotion and guiding the activities of ENHR,B. Subsequently, four more members were co-opted and it was made more broad based. The secretariat of ENHR was housed at BRAC.

ENHR,B was formally launched in November 1990 through a high level national workshop. In this connection a press conference was arranged and the concept of ENHR was shared with the journalists. Accordingly many of the daily English and Bengali papers brought ENHR to the notice of the general public and sensitized the community of the necessity of ENHR (Appendix-2).

During 1991, the ENHR movement in Bangladesh was strengthened by forming a 22-member "National Forum" to provide stimuli to the whole process of implementing ENHR in Bangladesh, and act as catalyst in the mechanism. Majority of the members (59%) of the "National Forum" were NGO leaders, leaders of health related national forums and leaders of women's organizations and senior academicians (Appendix-3).

The ENHR movement was further boosted up at the national level by organizing a national workshop in December 1991 with the "National Forum Members" and "Working Group Members". That workshop was also participated by a few (three) teachers of **community medicine** of medical colleges.

In order to bring ENHR to the notice of the general public, articles on the concept of ENHR movement and its activities undertaken in Bangladesh have been published in the daily newspapers from time to time. Some of the published articles were: (i) Effective Use of ENHR Urged, Daily Times, November 1989; (ii) Research Key to the Success of Health for All, The Daily Star (no date); (iii) Essential National Health

Research in Bangladesh, Dhaka Courier, 26 February 1993; and (iv) Bangladesh Tries to Come to Grips with Health Problems, Bangladesh Observer, August 18, 1994 ([Appendix-4](#)).

A Newsletter on ENHR,B titled "LIAISON: A Link Between Producers and Users of Health Research" was published ([Appendix-5](#)). Two issues of this Newsletter were published, one in 1994 and the other one in 1996. The Newsletters included articles on ENHR such as "Linking Research to Policy". It also included information on the activities of ENHR,B.

The Newsletters were widely distributed. Among others, the recipients of the Newsletters included a large number of NGOs, Women's Forums/organizations and academicians.

From the above discussions it is observed that there was broad-based representation of the stakeholders in health research in initiating the ENHR movement in Bangladesh. In other words, at the initial stage of ENHR in Bangladesh, the promotional and advocacy workshops and meetings were represented by **national level public representatives and opinion leaders, concerned groups of the civil society such as NGOs and women associations**, health service providers, health researchers, policy makers and program managers. Over the time, **people at large** were informed and sensitized through mass media about the philosophy of ENHR and the need of ENHR movement in the context of Bangladesh.

### 3.2. Community Participation in ENHR Mechanism

BRAC, the largest NGO in Bangladesh had taken the pioneering role in establishing ENHR in Bangladesh. Its secretariat is housed at BRAC. ENHR activities are guided by a group of people, termed as the "Working Group". Over the time, there were some changes in the "Working Group Members" and at present there are 12 members. Their composition is provided in [Appendix-6](#). The purposes of forming "Working Group" were to promote ENHR in the country by building research awareness and capacity, creating a positive research environment, stimulating demand for research in making policies, mobilizing resources for ENHR, disseminating research results etc. They belong to the following categories of institutions:

<u>Institution category</u>	<u>Number of members</u>
<b>NGOs</b>	<b>5 (3 national and 2 international)</b>
<b>University</b>	<b>1</b>
<b>Autonomous organizations</b>	<b>2</b>
Government academic/research/policy making	4

institutions

**Total:**

**12**

It can be seen that two-thirds of the "Working Group" members are from NGOs, academic institution and autonomous bodies. The members predominantly are from NGOs which are involved in the grass-root level programs. The Coordinator of ENHR,B is also an NGO representative.

### **3.3. Community Participation in Priority Setting**

The 1989 ENHR workshop emphasized community participation and a community-driven research agenda. Over two-thirds of the Working Group Members of ENHR are from NGOs and autonomous bodies. The priority areas of ENHR,B were identified by the Working Group and thus community participation in the process of priority setting was ensured. The priority areas included:

- community-based research on the incidence and/or prevalence of avoidable diseases
- socio-economic, cultural, religious, political and other behavioral constraints in relation to public health problems
- cost-benefit analysis, cost-effectiveness studies of various program modules or components, individually or mixed
- nutrition of high risk groups: women, adolescent girls and children under five
- urban health care
- policy related research
- environmental and occupational health

The perceptions of the general public on health and health problems collected through surveys/studies were considered in setting the research agenda.

The ENHR Working Group also developed a 10-year work plan (1990-1999), which included: forming a broad-based National Forum including representatives from the NGOs, Women's Organization/Women's Forum, and changing the curriculum of the medical colleges to emphasize more on **community medicine**.

### 3.4. Community Participation in Networking

The 1989 ENHR workshop organized by BRAC recommended to give support to the development of capacity in health research and information gathering activities through establishment of a broad-based multi-disciplinary network of institutions. It was suggested to form an ENHR "Network" or "Working Group".

#### 3.4.1. Organizational Network

Working Group: A "Working Group" of Bangladesh ENHR was formed in 1990 consisting of 9 members which was later expanded to 12 members and they are representatives from 11 different institutions. The category of institutions are as follows:

<u>Organization category</u>		<u>Number of institutions</u>
<b>NGOs</b>	:	<b>4</b>
<b>Autonomous Research Institution</b>	:	<b>2</b>
<b>Academic Institution (University)</b>	:	<b>1</b>
Government academic/research/policy making institutions	:	4
	<b>Total:</b>	<b>11</b>

Thus the Working Group is a network of 11 organizations of the country and about two-thirds (64%) of those organizations are NGOs/autonomous bodies, and most of these organizations have linkage with the grass-root level people.

National Forum: The National Forum of Bangladesh ENHR is a network of 22 persons from 20 leading organizations/agencies/institutions and 40 percent of them are NGOs, autonomous bodies and academic institutions, as can be seen from the following distribution of organizations:



<u>Organization category</u>		<u>Number of institutions</u>
<b>National NGO</b>	:	<b>1</b>
<b>International NGO</b>	:	<b>2</b>
<b>Women Forum</b>	:	<b>1</b>
<b>Autonomous Organization</b>	:	<b>3</b>
<b>Academic Institution (University)</b>	:	<b>1</b>
Development partner	:	1
Government institutions	:	11
<b>Total:</b>		<b>20</b>

#### **4.3.2. Workshop**

In order to establish linkage of ENHR with different institutions for coordinating and promoting essential health research, a workshop was organized by ENHR in June 1993 in collaboration with the government and development partners. A total of 47 high level persons from 36 organizations attended the workshop. One-third of the organizations attending the workshop were NGOs and 36 percent were development partner organizations. The workshop was also attended by representatives from two universities (5.5%). The remaining one-quarter of the organizations were government agencies.

The proceedings of the meeting were distributed to 70 persons of 45 organizations. The distribution of the category of those organizations are as follows:

<u>Organization category</u>		<u>Number of institutions</u>
<b>National NGOs</b>	:	<b>12</b>
<b>International NGOs</b>	:	<b>2</b>
<b>Autonomous Organization</b>	:	<b>3</b>
<b>Association/Forum</b>	:	<b>1</b>
<b>University/Educational institutions</b>	:	<b>3</b>
Development partner	:	12
Government institutions	:	12
<b>Total:</b>		<b>45</b>

About 47 percent of the organizations were NGOs/autonomous bodies/ associations/academic institutions. Over a quarter of the organizations (27%) receiving the proceedings were development partners.

### **3.4.3. Newsletter**

The Newsletter published by Bangladesh ENHR (mentioned earlier) was a mechanism to inform the general mass about ENHR and establish a network between ENHR,B and the people and organizations at large. Two issues of the Newsletter were published. The records show that a total of 208 copies of the first issue of Newsletter were distributed to different categories of people and institutions including people/organization at the sub-district level. The Newsletters were distributed to the following categories of people/organizations/agencies.

- ENHR Working Group Members
- ENHR National Forum Members
- National and International NGOs
- Different Institutions (government, autonomous bodies and educational institutions)
- Libraries
- ENHR Study Award Grantees and the Study Supervisors
- Development Partners

### **3.4.4. Research Studies and Publications**

Under a scheme of capacity building for young researchers, ENHR,B contracted out 18 research studies to 18 young researchers. All those studies gathered information from the rural/urban communities. Some of the studies used participatory method such as Focus Group Discussion in gathering information from the communities. The concerns and feelings of the community people on different health issues such as problems associated with safe motherhood, child care, drug addiction and post cyclone health problems have been identified. Though the interactions with the communities were of fleeting character, these provided rich information to understand the community in respect of their health needs. The studies have been completed recently and are ready for dissemination in a workshop to be participated by over 100 participants from different disciplines in the community.

ENHR,B prepared compendiums of researches done in the country in the recent years in some specific health areas. These helped in identifying the further research needs in those areas. The compendiums were circulated widely.

For example, volume IV of the compendium was distributed to 192 individuals/ institutions from different disciplines. They can be broadly classified as below:

• ENHR,B Working Group Members	:	13
• ENHR,B National Forum Members	:	22
• ENHR,B Research Award Grantee and Supervisor	:	21
• ENHR,B Studies Technical Reviewers	:	24
• Libraries	:	11
• Medical Colleges all over the countries	:	18
• Departments of Social Sciences of different Universities	:	16
• Health Related Government Institutions	:	28
• NGOs/Private Research Agencies	:	20
• Development partners	:	19
	<b>Total:</b>	<b>192</b>

### 3.5. Summary and Conclusion

#### 3.5.1. Initiation and Management of ENHR,B

ENHR,B was established with initiative from BRAC, which is a large NGO, and since its inception ENHR,B is housed at BRAC. Its activities are planned and guided by a group of persons termed as Working Group. A half of the Working Group Members are from various groups of the civil society. So it can be concluded that ENHR,B was formed by the community/civil society and its affairs are managed by a Working Group which is largely represented by the civil society.

#### 3.5.2. Promotion and Advocacy of ENHR,B

A number of activities were performed in the processes of promotion and advocacy of ENHR,B which includes:

- A national workshop which was organized in 1989. About a half (48%) of the participants in that workshop were from the civil societies such as NGOs and academicians.
- A follow-up of the 1989 workshop was held in 1990. A large majority of the participants (70%) in that workshop was from NGOs.
- During 1991, the movement of ENHR,B was strengthened by forming a National Forum. A large majority of the members (59%) in that workshop were academicians, NGO representatives, representatives of national forums and women's organization.
- The ENHR,B movement was further boosted up by organizing a national workshop with the National Forum Members and Working Group Members. That workshop also included a few teachers of

community medicine of medical colleges. In other words, that workshop was participated largely by the members from the civil society.

- In order to bring ENHR to the notice of the public, articles on the concept of ENHR movement and its activities undertaken in Bangladesh were published in the daily newspapers from time to time.
- A Newsletter on ENHR,B titled "LIAISON: A Link Between Producer and Users of Health Research" was published. Two issues of the Newsletter were published, one in 1994 and the other one in 1996. The Newsletter was widely distributed. Among others, the recipients of the Newsletter included a large number of NGOs, Women's Forums/organizations and academicians.

**From the above findings it can be concluded that representatives of most categories of stakeholders in health research participated in the activities for promotion and advocacy of ENHR in Bangladesh, and people at large were informed/sensitized about it.**

### **3.5.3. Priority Setting**

**The priority areas of activities of ENHR,B were determined by the Working Group. Two-thirds of the Working Group Members are from NGOs and autonomous bodies. Apart from this, the community's perceptions of health and health problems as identified through different community based surveys/studies were considered in setting the priority research agenda of ENHR,B. So it can be concluded that community participation in priority setting of ENHR,B was ensured.**

### **3.5.4. Networking**

- The affairs of ENHR,B are managed by the working group, which is a network of 11 different institutions. About a half of the institutions are NGOs and Non-government academic institutions.
- The National Forum of ENHR,B is a network of 20 organizations and a quarter of those organizations are NGOs/Women's Forum/Non-government academic institution.
- In order to establish network with different institutions for coordinating and promoting essential health research, a workshop was organized by ENHR in June 1993. Representatives from 36 institutions attended the workshop and 39 percent of those organizations were NGOs and autonomous academic institutions. The proceedings of the workshop were distributed to 45 institutions and 40 percent of those institutions were NGOs/Association/ Non-government research institutions.

- The Newsletter published by Bangladesh ENHR was a mechanism to inform the general mass about ENHR and establish a network among ENHR,B and the people and organization at large.
- ENHR conducted 18 research studies in rural/urban areas to gather information on the concerns and beliefs of the communities on different health issues, and many of those studies used participatory methods to gather the required information from rural/urban communities.
- ENHR,B prepared compendiums of researches done in the country in some specific health areas. The compendiums were circulated to the people and organizations at large.

**It is thus concluded that ENHR,B established a network largely with the civil societies i.e. NGOs/Associations/Forums and the people at large.**

## **SECTION FOUR**

### **GROUP DISCUSSION AND INTERVIEWS WITH STAKEHOLDERS**

#### **4.1. Group Discussion With Selected Groups of the Civil Society**

A discussion on community participation in health research was held with a group of senior executives and mid-level managers of NGOs and activist groups which work with grass-root level people. Some of those NGOs work for human rights (see Appendix-6). In their perception community is the grass-root level people. Since they did not have health research background and were involved in providing services to the people, most of them could not link health research with community participation. They were hinting more towards involvement of community in community development programs and community based services.

A few of them pointed out (others supported) that it was important to have the views of grass-root level people in settings health research agenda to reflect community's needs and concern about their health. In this regard, they suggested to hold discussion with the grass-root level people to understand their health problems, and accordingly the research agenda should be set. They also suggested that in setting health research agenda at the national level, views of people at different tiers beginning from the grass-root level should be considered.

They opined that communities' views can also be gathered from NGOs who work with grass-root level people. They added that mere discussion with NGO executives, who look after management issues and have little interaction with the community, will not reflect community's needs and perception. Discussion should be held with the group of NGO personnel who directly work at the grass-root level.

#### **4.2. Group Discussion With ENHR Working Group Members**

A discussion was held with some selected members of Working Group of ENHR,B on the issues of Community Participation in ENHR,B. They in general considered grass-root level people as the community. In respect of community involvement in health research they included all stakeholders in health research as community which in their opinion include policy makers, program managers, researchers, concerned groups of civil society and people at large. They however considered it more important to take the views and concern of grass-root level people in assessing health research needs.

When asked whether there was any community participation in ENHR activities, they considered that there was indirect community participation in ENHR,B, because many of the Working Group Members belong to NGOs which directly work with the grass-root level people and community's health needs and views are expected to be reflected through them. The members in general opined that the Working Group represents different stakeholder groups and they decide about the activities of ENHR,B and so there is community participation in ENHR,B. A few of the members opined that since the research studies of ENHR,B were done at the community level and that study information were gathered from grass-root level people, so it can be said that there was community participation in ENHR,B research studies.

## **Views Of Different Stakeholders On Community Participation In Health Research**

Views of stakeholders in health research were obtained by sending a questionnaire (see [Appendix-7](#)). It was sent to 26 persons and with repeated follow-up responses were received from 9 persons only. The summary of the responses by topic is provided below.

### **Understanding of Community**

Almost all the respondents considered grass-root level people as the community. Some of the respondents added that:

- a community is a group of people having same vocation or professional pursuit or ethnic/religious group
- potential beneficiaries of health services
- providers of services
- formal leaders i.e. elected representative of local government bodies
- informal leaders i.e. religious leaders, school teachers etc.

### **Importance of Involving Community in Health Research**

Except for one, all the respondents considered it very important. One respondent mentioned that community participation is important in formulating research problems and research methodology, if community is the study unit or beneficiary.

One social scientist stated that it is neither important nor appropriate to involve community in any kind of research. Their participation in health program activities is useful but their involvement in research is not important except that are to be taken as "research subjects".

### **Stages of Community Involvement in Health Research**

The respondents mentioned that community can be involved in health research at the following steps of research:

- Identification/defining/selection/understanding of research problems
- Developing the scope of the study to ensure that research has information on community priorities
- Designing data collection instrument



- Data collection stage
- Dissemination of research findings.

Most of the respondents opined that discussions should be held with community at the first stage of research i.e. identifying research needs.

### **Level of Community Participation Practised in Bangladesh**

Most of the respondents expressed that community participation in health research is seldom practised. One of the respondents said that community participation is ensured in those researches in which participatory method is used. Another participant mentioned that involvement of community in developing the scope of work/instruments of the study as well as dissemination of research findings at the community level have increased in the recent years, but is still very limited.

### **How Community Participation Can Be Promoted**

Many of the participants opined that community participation in health research can be promoted through the following activities:

- Inviting the community people to participate in health research seminars
- Sharing research findings with the community
- Sensitizing the health policy makers and researchers on promoting community participation in health research
- Organizing training/orientation courses on community participation
- Publication of professional journals in local language
- Using NGO-led association or groups at the grass-root level in mobilizing local leadership for participation in research project at the community level.

Note: Details of the responses are provided in the following pages.

## Views Of Different Stakeholders On Community Participation In Health Research

Sl. No.	Respondent	Understanding of community	Importance of involving community	Stages of involvement	Level of community participation in health research in Bangladesh	How community participation can be promoted
1.	Policy Maker	Grass-root level people	Considered very important	Data collection stage. It was added that in anthropological studies interaction with community is likely to be intensive.	To some extent	The community people should be informed that their cooperation will improve the quality of data collected from the community which will help the planners in doing realistic planning and eventually the community people will be gainer.
2.	Program Manager	Grass-root level people and different segment of beneficiaries of health research	Considered very important	Depends on the research question	Not much. But varies depending on the culture of research organization and individual researchers.	<ul style="list-style-type: none"> <li>- Generate community interest in health research. Invite the community to participate in health research seminars.</li> <li>- Talk to different segments of the community while investigating on different topics of health research.</li> <li>- Share research findings with the community and show how the community is going to benefit from health research.</li> <li>- Sensitize the health policy makers and researchers on promoting community participation in health research</li> </ul>

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3.	Women's Forum (Activist Group)	Grass-root level people	It was considered very important to get community's views and experience in health research.	From the identification of research question to the dissemination of research findings.	Community participation is ensured in those researches in which participatory method is used. But community participation is less practised in analysis and dissemination.	<ul style="list-style-type: none"> <li>- Orientation to researchers on the importance of community participation and inclusion of marginalized members of the community</li> <li>- Highlighting successful research done with community participation</li> <li>- Training course on community participation</li> <li>- Publication of professional journals in Bangla</li> </ul>
4.	Social Scientist	Grass-root level people	It is neither important nor appropriate to involve community in any kind of research. Their participation in health program activities is useful but their involvement in research as more than "research subjects" should not be appreciated.	In no stage	In general, the extent of participation is not much except a few research pockets (e.g. Matlab) in Bangladesh	In the first hand community participation in health research should not be promoted. But if someone wants to involve the community, the best way would be to use NGO-led association or groups at the grass-roots level. Such forums may be very effective in mobilizing local leaderships for research project at the community level.
5.	Social Scientist	A group of people having same vocation or professional pursuit. It may be a fisherman community, or a farmer's community or ethnic religious community.	Considered important	<ul style="list-style-type: none"> <li>- In defining research problems on health issues</li> <li>- Solution development and their validation</li> </ul>	Community participation is very seldom practised in health research.	Different research agencies/firms may be oriented on the importance of community participation in health research.

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6.	Development Partner	Grass-root level people	Considered important	<ul style="list-style-type: none"> <li>- In developing the scope of the study and designing instruments used in research. This ensures that research has information on community priorities, and on how to design instruments to get more accurate information.</li> <li>- In data collection because in health research community often is a major source of data collection.</li> <li>- Dissemination of research findings.</li> </ul>	<ul style="list-style-type: none"> <li>- The involvement of community in developing the scope of work of the study/instruments for the study has been increasing in the last 3-4 years, but is still very limited.</li> <li>- The dissemination of research findings at the community level has expanded in recent years, but needs greater emphasis.</li> </ul>	<ul style="list-style-type: none"> <li>- By raising awareness of the benefits of community participation in health research among all concerned groups: researchers, donors and policy makers.</li> <li>- Making community involvement an important element in implementing health research where its contribution can be significant.</li> <li>- Making allowance for financial, administrative and logistic costs of involving community in health research.</li> </ul>
7.	Development Partner	Grass-root level people: <ul style="list-style-type: none"> <li>- potential beneficiaries of health services</li> <li>- providers of services</li> <li>- formal and informal leaders i.e. elected representatives of local government bodies, religious leaders, school teachers etc.</li> </ul>	Considered important	<ul style="list-style-type: none"> <li>- Selection of research topic</li> <li>- Understanding the research issues</li> <li>- Sharpening the questions</li> </ul>	To a limited extend	<ul style="list-style-type: none"> <li>- Repeatedly asking the question to oneself, Institutions, Researchers and users of research results, that whether sufficient discussion and understanding reached to carryout a particular research or study in the health field.</li> <li>- Through extensive consultation at all levels a guideline/protocol be developed to understand the issue of community involvement in various types of research work.</li> <li>- Finally a checklist be there to see whether a particular research work fulfill the criteria of community involvement as per earlier agreed principle.</li> <li>- Commissioning any research work.</li> </ul>

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8.	Working Group	Grass-root level	Community	- formulating research	Not practiced	- Researchers should be

	Member ENHR,B	people	participation is important in formulating research problems and in formulating research methodology if community is the study unit or beneficiary.	- problem monitoring data collection		oriented - Funding may be conditional - Advocacy group may be formed
9.	Working Group Member ENHR,B	Policy makers, program managers and people at the grass-root level.	Considered very important	- Identifying research problems - defining solutions - implementing activities - monitoring and evaluation of the program	In a very limited scale in terms of participation of grass-roots level people	Sensitizing community members at all levels about the importance of community participation in alleviating health problems.

## SECTION FIVE

### CASE STUDY

#### **A Case Study On Community Managed Health Development**

Program for the Introduction and Adaptation of Contraceptive Technology (PIACT) Bangladesh undertook an operations research during the period 1992 to 1993 in a rural area of Bangladesh with a population of 25000.

The purpose of the operations research was to develop a model for self help of the rural community for the development of their health. In implementing the program, the following steps were followed:

- **Baseline Survey**

A baseline survey was conducted to collect information on prevalence of diseases at all ages; nutritional practices and nutritional status of mothers and children; prevalence of sanitary latrines and tubewells; and sources of health information and health services in the community.

- **Sensitization and Mobilization of the Community**

The community people were sensitized and mobilized about their health. This was done through acquaintance and interaction with the community.

For making acquaintance with the community, the study area was suitably divided into four units with around 6000 population in each unit. An organizer was assigned to each unit. He got into the community with certain program concept involving installation of tubewell and low cost sanitary latrine which were needed in the community and could have visible and immediate benefits. These needs of the community were identified through the baseline survey in the community.

After the organizer got acquainted with the community, he organized small group meetings to discuss about installation of tubewell and sanitary latrine and overall health related problems of the community and stimulated their thinking on what were their health problems and what they should do in improving their health situation.

In the process, individuals (of both sexes) were identified who could visualize the community health problems well and were found to have interest to get involved in solving the community problems. Those persons were met individually and/or in small groups to stimulate their thinking more and more about the health problems of their community. Such interactions continued until an interested group emerged who became concerned about the health problems of their community and were willing to participate in the process of solving those problems.

- **Formation of Health Club**

With the leadership of the community people who got interested in the process to solve the health problems of their community, a meeting was organized inviting all the people in the community (both male and female). The baseline health information data were presented in the meeting (separate meeting was organized in each unit). This was found instrumental in drawing the attention of the villagers. They got concerned about the health situation of their community and they began to interact among themselves about this. In the process they were asked to prioritize their health problems and determine which of the problems would require immediate attention, and how those could be solved. They performed the job where the organizer worked as a catalyst.

Discussions continued on what contributions the community people could make to solve their health problems. To continue their efforts for solving the health problem of their community, they formed a health club, elected a general body and an executive committee to carry out the activities of the club. The meeting also decided the location of the health club. In the subsequent meetings a constitution for the health club was developed.

A total of four health clubs were established each covering about 600 population. The health club was established with the purpose that it would be the focal point of health development activities in the community. The health club was also viewed as the primary center for health information, health education and treatment for minor ailments. It was planned to link up the community club with the community level government, non-government and private health workers and physicians as well as with the health centers at the union and thana level. It was also planned to generate income for the sustainability of the health club through some income generation activities appropriate in the local context by procuring resources from the rural development government and non-government agencies. The goal was that over the time the health club would evolve as the house of health information and a center for taking decision for the health development as well as the overall development of the community.

The study was for a period of two years. This two years' period was not sufficient to fully activate the health clubs and to make it sustainable with the management of the community

people without external technical assistance. However, among many others, the following lessons were learned from the operations research:

1. The village people are not health conscious and do not have the feeling that they live in unhygienic condition, but with appropriate interaction and participatory activities with community it is possible to sensitize and activate them to improve their health condition.
2. Sharing the health survey/research results with the community is instrumental to draw the attention of the community people to solve their health problems with their participation.
3. The community people are more interested in those programs which provide them direct and visible benefits, particularly those which would bring financial benefits. General health research/program alone is not attractive to them. But through dialogue and interactions with the community and enhancing their sense that they are important for the community and they can contribute significantly for improving the health condition of the community, they gradually develop interest in it.
4. Institutionalization of community health program is a long process, which however can be shortened with appropriate approaches and action.



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