

# **Community Participation in ENHR: Trinidad and Tobago**

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## **Final Report**

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### **Introduction**

The concept of Essential National Health Research (ENHR) was introduced to the Caribbean in 1992 when the Commonwealth Caribbean Medical Research Council (predecessor organization of the Caribbean Health Research Council) and the Council for Health Research for Development (COHRED) organized a Caribbean regional workshop on ENHR in Curacao in 1992<sup>1</sup>. CCMRC subsequently prepared a proposal for ENHR for the region<sup>2</sup> and this was adopted by Ministers Responsible for Health in the Caribbean in 1994.

In November 1995, Trinidad and Tobago along with Barbados, Curacao and Jamaica, sent a Team to a regional workshop in Jamaica to assist countries to set up ENHR in their countries<sup>3</sup>. On their return to Trinidad, the Team consulted with health officials in the government and the University and a national workshop on ENHR was convened to which representatives from key organizations, including NGOs were invited. A major decision taken at that workshop was the formation of a small steering committee to establish a proposal for the establishment of a national ENHR organization for presentation to the government for adoption<sup>4</sup>. To date, a constitution and a Chairman & membership of an ENHR Council of Trinidad and Tobago was agreed and a research study to compile a directory of health research studies and researchers<sup>5</sup> has been completed.

An essential element in the ENHR strategy is the involvement of the community which together with researchers and policy makers form the three interacting forces that shape action taken to improve health of the population. However, there is little systematic knowledge about how community participation actually operates to shape health policy or research and whether this process differs from country to country. COHRED therefore set up a Working Group on Community Participation in ENHR under the leadership of

Professor Susan Reynolds Whyte “*to examine how community participation has been defined, understood and practiced in countries trying to implement ENHR*”. Trinidad and Tobago along with five other countries were selected to take part in this multi-country study.

## **Setting**

Trinidad and Tobago is a twin island republic with a population of 1.2 million people, 50,000 of whom live in Tobago. Health care in Trinidad and Tobago is never simple. It operates against a background of multi-ethnic diversity, some poverty, some resource constraints and many vertical administrative structures which make it difficult to interrelate.

## **Population**

Forty percent of the population is of East Indian ancestry and a similar percent is of African ancestry. Most of the remaining population is of mixed ethnicity with small numbers of Caucasians, Chinese and other ethnic groups. Thirty per cent (30%) of the population is under 15 years of age, and six per cent (6%) is over 65. The bulge in population growth is currently in the 15-24 year age group, with 12% of the population being in this age band. In twenty years' time, the population over 65 will increase by 60%.

## **Socio-economic Features**

Despite having a higher Gross Domestic Product (GDP) than most Caribbean countries, approximately 25% of households live in poverty. The results of the Ability and Willingness To Pay Survey conducted in 1995 indicated that there is an even larger number of people who have low per-capita household expenditure (an additional 50%). Educational levels are good: 38% of the population over 15 have attained a secondary level education. In the recent National Health Survey, educational attainment was the only socio-economic variable that was consistently related to health status.

## **Economic Aspects**

In 1996, it was estimated that US\$167 million were spent on health, representing

about 5% of the GDP. Fifty per cent of this was spent in the government sector. The private sector expenditure is dominated by 'fee for service' primary-care services used by approximately 80% of households and estimated to cost US\$87 million per year (excluding drugs). Private hospitals are used by less than 10% of households and cost US\$100 million, whereas 90% of the population use public hospitals, which cost US\$360 million. The government also spent US\$97 million on primary health care and public health. In terms of pharmaceuticals, the expenditure is US\$300 million, of which more than 80% was spent in the private sector.

In a nutshell, serious health care is provided by the government sector, basic health care is split between the government sector and the private sector, but the type of care given is more preventive in the government sector and more curative in the private sector.

### **Regional Health Priority Areas**

**In 1986**, the Caribbean Community (CARICOM) Ministers Responsible for Health (CMH) adopted the Caribbean Cooperation in Health (CCH I) Initiative which initially targeted six **priority health areas** for the region:

- ◆ **Environmental protection including vector control**
- ◆ **Chronic diseases and injury prevention**
- ◆ **Strengthening of Health Systems**
- ◆ **Maternal and Child Health**
- ◆ **Human Resource Development**
- ◆ **Food and Nutrition**

A seventh priority health area was later added:

- ◆ **AIDS prevention and control**

**In 1991**, Goals and Targets<sup>6</sup> for these priority areas were defined and an appraisal of the CCH Initiative (1992-1994) found that overall, Caribbean countries had benefitted. **In 1996** the CMH re-defined and re-formulated the Initiative for the period 1997-2001. A wide cross section of national and regional professionals in health and planning from 19 Caribbean countries met and selected eight health priority areas (CCH II)<sup>7</sup>:

- ◆ **Environmental Health**
- ◆ **Strengthening Health Systems**
- ◆ **Chronic Non-Communicable Diseases**
- ◆ **Mental Health including Substance Abuse**
- ◆ **Family Health**
- ◆ **Prevention and Control of Communicable Diseases**
- ◆ **Food and Nutrition**
- ◆ **Human Resource Development**

The meeting also emphasized the importance of **Health Promotion**. A key strategy to implement this is “empowering communities to achieve well-being”.

***“Empowering communities to achieve well-being”.***

*Health promotion must build on that aspect of Caribbean culture that embraces community action and the tradition of the extended family. Communities will be provided with the information and tools to allow them to take such actions as are needed to improve health and well being. Proactive community action and participation, as well as the community’s involvement in determining its priorities for health promotion, must be acknowledged and facilitated by policy makers, health care providers and the media”.*

There is no specific Regional Health **Research** Agenda. However, in promoting and supporting regional health research, the Caribbean Health Research Council has used the regional health priority areas as a guide in determining the degree of relevance of research projects it supports. Another regional health organization, the Caribbean Epidemiology Centre, has conducted community-based research which has resulted in the development of communication campaigns targeting specific community groups but also the wider Caribbean populations.

## **Health Profile of Trinidad and Tobago**

The health status of Trinidad and Tobago, like the rest of the English-speaking Caribbean, has undergone significant changes consistent with those associated with epidemiological transition. Childhood mortality has decreased as life expectancy at birth has increased. These changes are associated with increased economic status within individuals and families, improved sanitation, personal hygiene and health care practices. Life expectancy at birth was 69.3 years for males and 74 years for females in 1990-1995.

The patterns of mortality and morbidity have changed over the last 30-35 years<sup>10</sup>. The proportion of deaths from communicable diseases, especially in the under 5 years of age, has shrunk while that from non-communicable diseases such as cancer, diabetes, hypertension and ischaemic heart disease, has increased. Thus in Trinidad and Tobago age-standardized mortality from diabetes mellitus increased in men from 60 in 1958-1962 to 278 per 100,000 population in 1988-1992. The corresponding values for females were 89 and 303. Ischaemic heart disease mortality has remained constant while there was a decline in mortality from hypertension<sup>10</sup>.

New and re-emerging diseases have appeared in the last two decades. Although their exact incidence and prevalence in the Caribbean are not known, sexually transmitted diseases (STDs) are on the rise, especially in the youth. Since 1992, there has been an explosive rise in the incidence of AIDS which is now the major cause of mortality in males and females aged 15-44 years.

The major health problems in Trinidad and Tobago are heart disease and stroke, cancer, diabetes, injury, and AIDS<sup>11</sup>. Communicable diseases are much less of a health problem than in the past, but have not disappeared. The number one environmental problem perceived by the public is the mosquito nuisance<sup>11</sup> (in this same study, 79% felt that this problem affected the health of their household).

## **Health System**

The health system in Trinidad and Tobago is being reformed. The final structure

will be a decentralized model: five regions or local health systems, each of which will have a hospital and a network of polyclinics and health centres. The Ministry has a new mission statement, the keywords of which are 'wellness', 'sustainable', and 'cost-effective'. They imply an emphasis on health promotion, the willingness to make choices based on evidence and a realigning of resource allocation. The achievement of some of these goals requires not only financial resources, but also respect for the value of the human resource in carrying out this mission.

### **National Health Research Priorities.**

The different kinds of research needed include:

Descriptive studies:

- ◆ Health needs assessments in order to allocate resources and make choices.
- ◆ Analytic studies: Why, what are the determinants of health, which factors would be beneficial to tackle?

Evaluations:

- ◆ Which interventions work, are cost effective, and which policies should be recommended.

### **Health Policy Development Process**

Decentralized Local Health Systems will establish Health Needs Assessment (HNA) units. It is too early to know how this will develop, but it offers great opportunity, **especially to involve the communities to participate in shaping health policy.**

### **Essential National Health Research in Trinidad and Tobago**

Several studies have been conducted in Trinidad and Tobago within the past few years which can be characterized as ENHR. Health research conducted in Trinidad and Tobago and the rest of the Caribbean is reported at the annual 2½ day scientific meeting organized by the Caribbean Health Research Council. In an analysis of the papers presented at these meetings for the period 1956-1995, papers were classified into **Clinical Studies,**

**Epidemiological and Community Health, Health Services Research and Laboratory Studies**<sup>12</sup>. Most papers were in the category of **Clinical Studies** until the 1990s declining from 45% initially to 25% in 1994. **Health Services Research** papers constituted about 40% in 1994. **Epidemiological and Community Health** papers have been between 10 - 15 % over the years, whilst **Laboratory Studies** have declined from 30 to 20%. A more detailed analysis was done on the abstracts of papers presented at the 1997<sup>13</sup>, 1998<sup>14</sup> and 1999<sup>15</sup> CHRC meetings in which papers were classified into the eight **regional health priority areas** plus ‘**others**’ . Results showed that an average of 79% of papers were in the eight health priority areas. Research was conducted most frequently on the chronic non-communicable and communicable diseases (about 25% each), followed by strengthening health systems and family health (please see Table).

However in none of the 337 papers read by one of the authors was it explicitly or implicitly stated that there was consultation with the community of its leaders in the selection, design or implementation of the research.

## **Community Participation in Essential National Health Research**

Purpose:

The objective of the study was to examine how community participation has been defined, understood and practiced in **the context of** Essential National Health Research in Trinidad and Tobago.

### **Methodology**

The research was carried out by the Principal Country Investigator and a Research Coordinator and this team was supported by Professor Susan Reynolds Whyte and a research advisory group (RAG) comprising four members of the ENHR Council.

The role of RAG was to oversee and advise the research team on the best possible approaches for the study and met with the research team on a two monthly basis to review progress and to make recommendations to facilitate the research.

The study was carried out through three processes:

- i. individual interviews with key informants and
- ii. focus groups with relevant communities.
- iii. Analysis of case studies: a research project involving the community and an experience in community mobilization in support of a proposed research project

Separate interview guides were developed for key informants and focus groups, reviewed by the RAG and approved for use in the study.

### **Individual Interviews**

Key informants were chosen from a list of researchers submitting research papers to the Caribbean Health Research Council (CHRC) as well as a list of participants of the inaugural meeting of the ENHR Council. The majority of key informants worked in the Government Service of Trinidad and Tobago including the Ministries of Consumer Affairs, Health and Sport and Youth Affairs. Other key informants were involved in the University of the West Indies Community Health Programme, the Health Economics Unit and the Department of Sociology as well as physician members of the Caribbean College of Family Practitioners. Key informants could be categorized into two groups: group one comprised persons who were engaged in health or health-related activities. Group II informants were in non-health related areas such as consumer affairs, sport and youth, etc. Interviews were conducted in the workplace using the interview guide.

### **Focus Groups**

Focus groups were selected from Non-Governmental Organizations (NGOs) and Community Based Organizations (CBOs) including the Diabetes Association, Narcotics Anonymous, Substance Abusers, Alcoholic Anonymous and Community Action



Resource(CARe) consisting of people living with HIV/AIDS. Leaders of these groups were contacted and appointments were made for the conduct of focus group sessions using the focus group interview guide. Sessions involved an average of about ten individuals and lasted about 1 to 1½ hours.

### **Analysis of Case Studies**

The first case study involved a review of a research project entitled “*Community Participation in Dengue Prevention and Control: A Survey of Knowledge, Attitudes and Practices in Trinidad and Tobago*”. The second case study analysed was an experience in community mobilization in support of research: development of a Community Advisory Board in support of HIV/AIDS vaccine trials in Trinidad and Tobago.

### **Constraints in Data Collection**

Two constraints were encountered in collecting the data. Firstly, the original intention was to conduct interviews with twenty key informants. After thirteen interviews were completed, it was found that those informants who were in non-health related areas had only a limited knowledge of ENHR and could provide little information on community participation in ENHR. It was therefore decided to discontinue interviews with other informants in non-health related areas.

The original plan was to convene a focus group in Toco, a rural area where one of the case studies, “*Community participation in Dengue Prevention and control: A survey of Knowledge, Attitudes and Practices in Trinidad and Tobago*”, was conducted. However, several attempts to convene this group were unsuccessful due to difficulties in communication with this isolated and remote area. Eventually a decision was taken to omit this group from the study.

## **Results**

### **Key Informants**

A total of thirteen key informants were interviewed using the interview guide. This focused on:

- ◆ *knowledge of ENHR*, including its definition and elements;
- ◆ *description of community* , including internal social & political structure, attitudes and expectations as they relate to the research study;
- ◆ *community participation*, including how they were chosen and contacted, their levels of involvement in the research process, whether their primary concerns were expressed and incorporated into the research process, if and how the community was informed of the results and how these results were used by the community;
- ◆ *assessing community participation*, including how communities perceived and assessed their involvement in the process, and how researchers perceived and assessed the communities' actual involvement.;

#### *Knowledge of ENHR*

The majority of researchers in health or health-related activities (Group I) were aware of Essential National Health Research. These informants had a deeper appreciation of ENHR and how their research related to ENHR. In contrast, key informants in Group II had less of an appreciation of ENHR. Their recollections go back to the convening of the first Council meeting.

Neither of the two groups could identify the components of ENHR. Many admitted receiving documents explaining ENHR but had not thoroughly read them. All of them eventually considered their research part of ENHR.

Most researchers gave as their reasons for engaging in the research, policy development and improving the quality of service delivery. No researcher gave publication of the work and academic advancement as reasons for conducting the research.

### *Description of Community*

- i. All researchers stated that the community was involved in the research they had done. Where studies were epidemiological and quantitative in nature, representative samples of the community of interest were randomly selected using statistical data from the Central Statistical Office. Variables used to describe community included geography, household composition, gender, age and ethnicity. In contrast, community was described in clinical studies as hospital in-patients or out-patients with specific diseases or conditions.
- ii. In general, there was hardly any involvement of the community in the studies reported by the informants (community in this context refers to community in a geographical or disease-specific sense). In the majority of these studies, there were no community organizations speaking for the community. Participants were identified via household sampling as described above.

Researchers reported that subjects were individually asked their consent to participate in the study. Nearly all subjects agreed to participate and consent was given orally rather than in writing.

Key informants indicated that their research results were or could be used to inform programme intervention, improve service delivery or assist in policy development. Research collaborators included other ministries or departments, institutions of higher learning, e.g. University of the West Indies as well as collaborators outside of the region.

### *Feedback*

All researchers admitted that they did not return to the participating community with the results of their studies although they agreed that this was useful. However, they acknowledged that through the development of policy and programs, the participating community received indirect benefits. Some researchers stated that while research results could be used to guide policy, at times there was tension

between policy makers and researchers depending on the research results and as such, many useful studies have been shelved.

### **Focus Groups/Community**

Data were obtained from the following four focus groups: Substance Abusers, People Living with HIV/AIDS, Union Members and Public Servants.

We focused on the following issues:

- i. What were their important health issues
- ii. Where did they get information on these issues
- iii. Awareness of local research in these areas
- iv. Level of participation in the research process
- v. Feedback of results: did it occur? What were the best ways for providing feedback
- vi. Should the community be involved in the research process, and what form should this involvement take

#### *Knowledge of ENHR*

None of the individuals or groups representing community were aware of ENHR nor could they identify elements of it.

#### *Describing Community*

In this instance, groups defined themselves as having shared interest in a situation or issue, e.g. People Living With HIV/AIDS (PLWHA) community. They also felt that communities could be defined on the basis of geography. The groups believed that their participation in the research process was relevant and they suggested that many of the areas of focus for researchers were of little significance to them as a community. When each group was asked what areas should research focus on, their

responses included:

*i. Substance Abusers:*

- ◆ causes of drug addiction and reasons for relapse
- ◆ relationship between HIV infection and drug addiction
- ◆ relationship between substance abuse and crime

*ii. People Living with HIV/AIDS*

- ◆ clinical trials on new anti-retroviral drugs
- ◆ sexual practices and quality of life of people living with HIV/AIDS

*iii. Union Members*

- ◆ industry-related illnesses and,
- ◆ prevalence of work-related accidents and the resultant man-hours lost
- ◆ the above issues related to their concerns for an improved policy for occupational health and safety

*iv. Public Servants*

- ◆ feasibility of group insurance schemes for public servants
- ◆ levels of personal expenditure for drugs and other medications for treatment of common diseases such as diabetes, hypertension, asthma, etc
- ◆ efficacy of alternative medicine

*Feedback*

Focus groups supported the idea that all results of studies should be made available to the public at all levels of the society including young people in schools. The print and electronic media were seen as the vehicle for feedback. Research participants should be given direct feedback and prevention programs developed in order to reduce the impact of the health situation on the present and future generations.

*Perception of Research and Researchers*

Community groups felt that the general population, and researchers in particular,

believed that people in the community had only their self-interest at heart as opposed to the welfare of the community at large. The focus groups believed that researchers should work with and train the various stakeholders in participating in the research process, including conducting their own research. This would enable them to benefit from and participate in any interventions coming out of the research.

## **Case studies**

*“Community participation in Dengue Prevention and control: A survey of Knowledge, Attitudes and Practices in Trinidad and Tobago”.*

This study attempted to ascertain the knowledge, attitudes and practices in Trinidad and Tobago as it relates to dengue prevention and the eradication of the *Aedes aegypti* mosquito. While there have been considerable gains achieved in the hemisphere in the efforts to eradicate the *A. aegypti* mosquito, some forty years later these efforts were not sustainable. Due to scarce resources and limited manpower, programs have shifted focus from eradication to control of the mosquito with community based programs holding considerable appeal because of their potential to reduce demands on these already limited resources.

The global re-emergence of dengue and dengue haemorrhagic fever (DHF) as an important public health problem reflects the difficulties in maintaining effective vertically-organized control programs and highlights the urgent need to develop alternative sustainable, integrated approaches to *A. aegypti* control with community participation as a key intervention strategy.

In support of a regional initiative to reduce the risk of dengue transmission in select Caribbean islands by introducing community participation as a central tenet of vector control programs, this study was designed to systematically solicit

community input for program planning in Trinidad and Tobago. Knowledge, attitudes and practices were measured using two methodologies —the first a questionnaire administered by trained interviewers to be answered by the household respondent, the second a mosquito larva survey of household compounds carried out by trained vector inspectors to identify potential and actual mosquito breeding sites in the corresponding households. The use of the two instruments allowed for comparison of respondent knowledge, attitude and reported practice with the actual condition of the compound. Prior to the preparation of the two instruments, in depth interviews were done in urban and rural Trinidad in order to provide further insights into community perceptions of pest control and environmental sanitation. This allowed researchers to develop an appropriate survey instrument for the national survey.

A sample of households representative of the Trinidad and Tobago population based on the 1991 census was selected. A two-step sampling procedure which combined a purposeful selection of communities and a random selection of clusters of households was used. Seven districts were selected for their overall geographic, socio-economic and ethnic representation of the twin-island nation.

A total of 591 interviews were conducted throughout the country and 753 household inspections were carried out. The urban/rural household ratio was approximately 2:1 reflecting Trinidad demographics. The survey was carried out during the dry season of 1992 during the months of November and December.

### **Results**

Rats and mice were most frequently identified by respondents as the most annoying environmental sanitation problems in Trinidad and Tobago, followed by night-biting mosquitoes and day-biting *Aedes aegypti*.

The data demonstrated key relationships between knowledge, experience with

dengue fever and household pest control activities. The research clearly supports the adoption of a comprehensive approach to *Aedes aegypti* control replacing the more vertical approach that concentrates on the control of *Aedes aegypti* without consideration of the greater water, pest and sanitation issues confronting communities. While awareness was high on the seriousness of dengue and its causes, prevention behaviour among householders did not reflect this concern. The data indicated that Trinidadians expected the Government vector control division to play a major role in pest control.

We would conclude that if the community had been asked to identify and define the most pressing environmental issues, it is likely that the research and intervention would have been different, i.e. a more integrated approach to pest control.

***Development of the Community Advisory Board in Support of HIV/AIDS Vaccine trials in Trinidad and Tobago***

The first case of HIV/AIDS in Trinidad & Tobago was reported in 1983. Fifteen (15) years later, the epidemic has exploded in such a way that it has touched thousands of lives and families. Trinidad and Tobago, like other Caribbean countries, can boast of a National AIDS Programme that has promoted well accepted preventative measures. In particular, it has educated the population so that more than 70% can accurately recall the various modes of HIV transmission as well as the recommended prevention strategies including consistent condom use and reduction in the number of partners. However, the number of cases of AIDS continues to rise among men, women and children with the burden of the disease reflected in the age group 15 - 44.

The Caribbean is second to sub-Saharan Africa in terms of HIV prevalence rate. A review of the region's data places Trinidad and Tobago as a major contributor to the high prevalence of HIV in the Caribbean.. It is natural then, that a discussion surrounding



vaccines and vaccine trials would have come to our country and that the major sectors of the community would have an opinion on this and therefore should be given a voice.

Approximately one and a half years ago, the Medical Research Foundation, a private organization in Trinidad & Tobago, was informed that it's bid to the National Institutes of Health, U.S.A., to become a trial site in the UNAIDS international quest for a vaccine had been successful. This meant that there was then the need to engage in one year of vaccine preparedness for the Trinidad and Tobago national community. Preparedness measures included the development of,

- ◆ state of the art laboratory capabilities to perform tests relevant to the study of HIV/AIDS
- ◆ behavioural studies related to research and treatment compliance, and willingness to participate
- ◆ internal review boards to address ethical issues related to the use of human subjects in research
- ◆ community mobilization and organization to serve as a watch dog on behalf of the general community including participants in the study (Community Advisory Board).

There was agreement among the international and local agencies involved, that the trials will not be undertaken without the consent of the government and the assent of the people of Trinidad and Tobago. In order to begin community mobilization and organization, two community leaders involved in HIV work were commissioned to convene a meeting of significant NGOs and individuals for participation in the formation of a community advisory board..

At the meeting were representatives of the disciplines of medicine, social work, health education, the clergy, psychology, and teaching. Also present were people living with HIV/AIDS, relatives of individuals who had died from AIDS, AIDS activists, and

advocates of women's issues and family planning. All present had been privy to articles published in the press referring to the issues of vaccine trials beginning in Trinidad & Tobago and the Bahamas. A presentation was given of HIV vaccines and vaccine trials in general. The meeting also presented an opportunity for participants to interact with the local principal investigator in order to clarify exactly what action was involved in the proposed vaccine trials in Trinidad and Tobago.

### **Community Concerns**

Participants in this initial mobilization meeting voiced the following questions and concerns:

- ◆ details on the safety and side effects of the vaccine
- ◆ whether previous trials had been done, where, and whether there was documentation from individuals (personal testimonies) who were volunteers in the study.
- ◆ behavioural research surrounding the motivating factors for volunteering for such a study.
- ◆ the cultural diversity of the two islands and the distinct difference in the media and method of reporting
- ◆ the response of the religious community to aspects of certain of the AIDS interventions (working with gay men and prostitutes and the promotion condoms) and the need to nurture a positive relationship with the various religious organisations
- ◆ whether the Ministry of Health had given its support for the trial and what were its responsibility to inform the public about the trial
- ◆ participation in trials and benefits for persons already infected with HIV
- ◆ legal and ethical issues surrounding the effects of participation in vaccine trials on an individual's day to day life
- ◆ what other sites would be involved in the present phase of the study
- ◆ the development of a media strategy for informing the population on a continuous basis as well as the media's ability to understand the scientific nature of the study
- ◆ issues of confidentiality surrounding the trial volunteers,

- ◆ the fact that any discussion on vaccine trial might create a false perception of cure and might increase risk behaviour especially among the young,
- ◆ the perceived lack of interest by the medical community in general on HIV issues.

### **Community Expectations**

The participants also outlined a number of expectations which they had for those agencies and groups involved in the exercise, and which were paramount to the Community Advisory Board as they developed.

These included:

- ◆ informed consent must include the consent of partners, and family consent for siblings and/or children to participate in such a study,
- ◆ a commitment by the Government to make evident its recognition of HIV as a priority by its level of support afforded to the National AIDS Programme, i.e. financial and human resources, as well as the development of a national policy on AIDS. The group lamented the disappearance of the staff of the National AIDS Programme and with this, its ability to implement interventions in the community.
- ◆ the provision of overall national benefits in support of the HIV/PWA community in Trinidad and Tobago, e.g. reduced medication costs, or supply of medication to treat opportunistic infections (Septra, Diflucan, Zovirax) which are not consistently available at public hospitals, AZT for pregnant mothers and viral load testing.
- ◆ training for nationals including general practitioners in the clinical management of HIV.
- ◆ twinning of local AIDS service organizations with international NGOs for technical assistance and financial support.
- ◆ development of strategies to work with families of people with AIDS to encourage them to organise and share with the rest of the community with a view to supporting prevention and encouraging mental and emotional healing.

While the CAB was being formed various influential individuals in the national community used their accessibility to the media to add their voices to the national debate on

vaccine trials. These voices included members of the clergy, public service employee union leaders, medical association physicians, anthropologist as well as outraged citizens. There was also a radio call in poll on whether there should be trials. The Ministry of Health used every opportunity to inform the public that a formal protocol for the trial had not yet been received and therefore approval had not been given for the trials. The Ministry had formed an ethics committee to look closely at the issues relative to the trials.

As every new article or voice was added, the local principal investigator responded. He was doing one of the following, setting the record straight on the stages of preparedness, stages of vaccine trial which was being proposed, as well as his own need to be sure that the trials were safe and conducted in an atmosphere of transparency. This individual sort to allay the fears of the population, as well as to challenge some of the voices who set themselves as authorities on the issue.

Though the furor has died down, at the time of writing, a protocol was not received and so the government has not given permission for the trials to proceed. Those involved in the preparedness exercise continue and the CAB continues with its work to educate itself and the public on HIV/AIDS issues and vaccine trials.

## **Conclusion**

1. There has been minimal community involvement in individual health-related research studies in Trinidad and Tobago. However, specific communities have identified areas where research was needed, as shown in our discussions with the focus groups.
2. Community involvement in ENHR consisted, in the main, of being a subject in a

research study.

3. There is a healthy and growing research environment in which the majority of research can be classified as ENHR, although knowledge of ENHR among researchers as well as the public is limited.
4. The case study on community participation in dengue prevention demonstrated *“that if the community had been asked to identify and define the most pressing environmental issues, it is likely that the research and intervention would have been different, i.e. a more integrated approach to pest control”*.
5. Our analysis of the development of the Community Advisory Board clearly indicates that the community at large, i.e. the public, is interested in and willing to participate in all aspects of ENHR if the right mechanism is developed to engage the community.

**Table: Classification of Papers from Caribbean Health Researchers Presented at Caribbean Health Research Council Scientific Meetings for the years 1997 - 1999<sup>1</sup>**

<b>Year</b>	<b>No. Of papers</b>	<b>Environmental Health</b>	<b>Strengthening Health Systems</b>	<b>Chronic Non-communicable Diseases</b>	<b>Mental Health</b>	<b>Family Health</b>	<b>Communicable Diseases</b>	<b>Food and Nutrition</b>
1997	105	2.9%	12.4%	24.8%	5.7%	6.7%	20.8%	1.9%
1998	111	2.7%	8.1%	22.5%	5.4%	12.6%	21.6%	4.3%
1999	130	3.8%	11.5%	27.7%	3.8%	8.5%	16.9%	1.5%
<b>Mean</b>		<b>3.1%</b>	<b>10.7%</b>	<b>25.0%</b>	<b>5.0%</b>	<b>9.3%</b>	<b>19.8%</b>	<b>2.6%</b>

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1 Based on papers presented at the Caribbean Health Research Council's annual scientific meetings in 1997, 1998 and 1999

## **Review of Documentation**

### **A. Establishment of ENHR in Trinidad and Tobago:**

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1. Report: Regional Workshop on Essential National Health Research, April 27-28, 1992, Curacao
  2. Essential National Health Research for the Caribbean: a proposal prepared for the Caribbean by the CCMRC, 1994
  3. Report on the CCMRC - COHRED Workshop on "Essential National Health Research and Priority Setting in Health Research", Jamaica, November 6-8, 1995.
  4. Report of a Workshop on Essential National Health Research, Port of Spain, Trinidad, 26-27 April, 1996
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### **Error! Main Document Only.. Regional Health Priority Areas**

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