# **CCMRC / COHRED**

# Regional Workshop on Essential National Health Research and Priority Setting in Health Research

Ocho Rios, Jamaica November 6 — 8, 1995

Report of the Workshop, including progress reported by the participating countries at the Follow-up Meeting in Trinidad, 19 April 1996

BARBADOS — CURAÇAO — JAMAICA ——
TRINIDAD AND TOBAGO

CCMRC / COHRED REGIONAL WORKSHOP ON ESSENTIAL NATIONAL HEALTH RESEARCH AND PRIORITY SETTING IN HEALTH RESEARCH, OCHO RIOS, JAMAICA, NOVEMBER 6 – 8, 1995

### **EXECUTIVE SUMMARY**

The goal of **Essential National Health Research** (ENHR) is to promote health and development on the basis of equity and social justice. Its emphasis on people, on their development and participation is its special feature. Few Caribbean countries have been able to formulate plans, or to implement and manage programmes of research to adequately meet this emphasis.

On behalf of the Commonwealth Caribbean countries, the Commonwealth Caribbean Medical Research Council ( CCMRC ) prepared a **Proposal for ENHR for the Caribbean**, and the Conference of Ministers Responsible for Health endorsed this proposal at their meeting in St. Vincent in 1994. The **objectives** of the Proposal are to plan and implement national and regional research projects based on the region's health priority areas, to increase the region's research capability and to promote, support and coordinate research and training activities in the region.

Caribbean governments have identified major problems in the operation of their health services and have embarked, or are about to undertake, significant **reform of their country's health sector**. Ideally, such an undertaking calls for critical decisions based on objective analysis of reliable available data and on results of carefully designed research studies. These activities are an example of ENHR at work. Health sector reform also provides a unique opportunity for Caribbean countries to assign a more meaningful and practical role for health research within the health sector.

In order to accelerate the process of establishing ENHR in the Caribbean, CCMRC and the Council on Health Research for Development (COHRED) convened in Jamaica a two-and-a-half-day Workshop on Priority Setting for Health Research in the Caribbean in the context of ENHR. The Workshop was attended by teams of four to five members from Barbados, Curaçao, Jamaica, and Trinidad and Tobago, and resource persons from the Caribbean, Kenya, South Africa, and Thailand. The objectives of the Workshop were to facilitate the team members' understanding of the ENHR strategy; for the team members to review their countries' health research priorities, to develop country-specific plans of action for ENHR, and to collaborate in the further promotion and implementation of Essential Regional Health Research for the Caribbean.

**During the Workshop**, participants identified and examined problems and issues in implementing health research in their countries. They critically reviewed mechanisms for priority setting for health research in the Caribbean, and discussed how these could be improved. Finally, each country team prepared a draft country plan of action for ENHR and regional proposals for collaboration in ENHR activities in the Caribbean. It is anticipated that country

teams will continue to promote and develop ENHR activities on their return to their home countries.

On the occasion of the 41st Meeting of the CCMRC, a meeting was convened on 19 April 1996 in Trinidad, where representatives of the four country teams presented reports on the progress made since the Ocho Rios Workshop, and they updated their plans of action. Brief summaries of these progress reports are included in this report.

### INTRODUCTION

Country teams representing Ministries of Health, academic and research institutions, and non-governmental organisations from Barbados, Curaçao, Jamaica, and Trinidad and Tobago attended the Workshop. Resource persons from the Caribbean, Kenya, South Africa, and Thailand facilitated the Workshop. It was expected that the Workshop would assist the team members in

- understanding, advocating, promoting and supporting the development of Essential National Health Research in their respective countries;
- assessing the critical and essential role of health research priority setting in the national Health R & D process;
- contributing to the development and implementation of a plan of action for health research priority setting within the context of an ENHR strategy;
- collaborating in the further promotion and implementation of a regional ENHR strategy.

The Workshop consisted of three parts:

- A. A general overview of ENHR concepts and (country, regional and global) developments and practices, introduced by the resource persons. During the discussion, participants identified some generic issues and problems;
- B. Presentations and discussions of the health status and current health research activities in the respective countries;
- C. Development by the country teams of draft Plans of Action for the implementation of ENHR.

The Workshop Programme and the List of Participants are included in Annex 1 and Annex 2, respectively, to this Report.

# SUMMARY OF GENERIC ISSUES AND PROBLEMS IDENTIFIED DURING THE WORKSHOP

#### **Problems**

1. Perception of health research (HR).

Most HR now academic, institution-based and oriented to medical model of health.

2. Need for definition/clarification of HR through:

Written policies/plans.

Budgetary allocations.

Clarification of roles and responsibilities.

Relevance to health needs.

#### 3. Coordination.

Lack of coordination and collaboration among individuals, interest groups, agencies and institutions carrying out research, resulting in unnecessary replication of data.

Lack of formal structure — ad hoc research activities.

Lack of involvement of communities and, to a lesser extent, lack of involvement of health professionals working in the community, in the planning, implementation and evaluation of research.

#### 4. Communication.

Lack of communication and feedback among the three main constituencies, i.e. researchers, decision-makers and communities, and among different disciplines.

5. Political interference/inertia.

If results not favourable, or deemed offensive to political directorate, they may be ignored or censored.

6. Limited human resources.

Researchers often have heavy case loads and competing dayto-day activities.

Lack of research skills results in questionable quality of data and results.

#### 7. Funding.

Limited country funds for research.

Difficulty accessing external funds.

#### **Priority Setting Mechanisms**

1. No national mechanisms.

- Individual or group interest determines priorities, which are implemented in an ad-hoc manner. They may not be hindered by government, but often not helped either.
- Curaçao recently completed an assessment of needs and burden of disease in the population, to assist in determining priorities. Planned and implemented by a public health interest group and funded by the Government of the Netherlands.
- 2. Research projects are donor- or programme-driven
  - Annual Survey of Living Conditions (SLC) in Jamaica sets research agenda, but final decisions taken in collaboration with the World Bank, which funds the SLC.
  - In Trinidad and Tobago, research related to Caribbean Cooperation in Health (CCH) priority areas, but no clear mechanisms in place for priority-setting within that framework. Currently, in context of Health Systems Reform (HSR), patient satisfaction and general health status being examined.
  - Barbados guided by a Development Plan, but no clear mechanisms for priority-setting.
  - In general, funding guides research and donor interest guides funding. Funding should be guided by priorities, but gaps often exist.

#### **Improvements**

- 1. Population needs assessment studies being conducted to inform priority setting (in addition to epidemiological data).
- 2. New research culture.
  - Demystify research; move concept from academia and medicine to the wider community; increase communication within the University and between the University and the wider community.
  - Emphasise operational research, i.e. research for decisionmaking, in order to improve the health of people, not for propaganda, or solely because of the 'publish or perish' rule existing in many academic institutions.
  - Training in research methods, to improve data quality and increase human resources available to conduct appropriate research.
  - Foster respect for quantitative as well as qualitative data through dialogue between different sectors and disciplines.
- Development of a national body which brings together disciplines and sectors to ensure collaboration and cooperation while discouraging replication of research. Define partnerships, roles and responsibilities. Strengthen ongoing research, in the current climate of health systems reform.

4. Address national priorities.

Provide justification to donors.

Strategic planning to ensure that donors accept country priorities.

- 5. Better communication, reporting and feedback among constituencies, in language tailored to the particular audience; make data available at all levels.
- 6. Greater commitment to research to determine priorities and use of the results at decision-making levels.

# COUNTRY PRESENTATIONS AND DRAFT PLANS OF ACTION

#### **BARBADOS**

#### **Background**

Barbados is the most easterly of the Caribbean Islands, located at 13 degrees North Latitude and 59 degrees West Longitude. Inhabitants are reminded of this every hurricane season when the winds blow from the West African Coast. The island is a relatively flat land mass of 430 square kilometres (166 square miles).

The system of government is a parliamentary democracy fashioned on the Westminster model. Although Barbados is an independent country, Her Majesty the Queen of Great Britain has been retained as the Head of State.

The economy of Barbados has been showing some decline, and the process of economic restructuring continues. The per capita income at factor cost was US\$5,600 in 1991, and the main economic activities are tourism, agriculture, and manufacturing.

The island is heavily populated at 599 persons per square kilometre. Estimations of the mid-year population based on the 1990 census was 257,082, 52% of whom were female. Life expectancy is 75.2 years for females and 70.2 years for males. There is almost zero population growth (0.2% since 1980).

The country is in epidemiological transition, with infections being replaced by chronic non-communicable diseases as the main causes of morbidity and mortality. The five leading causes of mortality are heart disease, malignant neoplasms, vascular disease, diabetes mellitus, and other diseases of the circulatory system. These accounted for 68% of the deaths between 1990–1992.

The infant mortality was 15.3/1,000 in 1990. The principal causes of death in children under one year are perinatal conditions and congenital abnormalities. The maternal death rate is low at 0.9/1,000. This reflects the high quality of antenatal care that the Maternal and Child Health programme delivers through an island-wide system of eight polyclinics. This health care is provided free of charge.

In terms of morbidity, information is available from two sources — hospitals and primary care services. Morbidity data from the latter are not analysed to any extent.

The ten leading discharge diagnoses based on hospital morbidity data are:

Direct obstetric causes

Diseases of the circulatory system

Malignant neoplasms

Diabetes mellitus

Abortion

Diseases of the eyes

Diseases of the upper respiratory tract (asthma)

Diseases of the urinary system Diseases of the skin.

#### Specific Health Problems

<u>Under 5 Years</u>: The main problems are conditions originating in the perinatal period, diseases of the respiratory tract (asthma), and congenital abnormalities. There is universal immunisation within the EPI programme with coverage in excess of 80%.

Adults: Chronic non-communicable diseases are the main causes of death and chronic illness in the adult population. These include diabetes mellitus, hypertension, and psychiatric disorders. The major causes of morbidity in the 15–44 years age group are social violence, i.e. attempted suicide, vehicle accidents, and injuries inflicted by other persons.

The prevalence of HIV is 1 in 250, and up to June 1995 there were 550 cases of AIDS with 78% mortality. The most important malignant neoplasms are cancer of the cervix, the breast, and the prostate.

<u>Elderly (> 65 years)</u>: The major diseases in this age group are arthritis, diabetes mellitus, and hypertension. Results of the Barbados Eye Study indicated that open-angle glaucoma and cataracts are also important.

<u>Notifiable Diseases</u>: These include food-borne diseases, gastro-enteritis, and Dengue fever (a vector-borne disease).

#### Other Areas of Concern and Current Initiatives

The Inter-American Development Bank (IADB) has given funding to investigate and pursue the rationalisation of care for the geriatric population (11 % of population is over 65 years); mental care services; and rehabilitation services. This current initiative highlights the issue of **technology transfer**, i.e. training of local counterparts to use state-of-the-art technology.

There is also a Pan American Health Organization (PAHO) funded project (through the Caribbean Cooperation in Health Initiative) to reduce the prevalence of carcinoma of the cervix.

#### Health Research

At present, there is no formal national programme of research priorities. However, there is a limited amount of research in lifestyle-related and chronic diseases. These efforts are mainly on an individual basis, and there is no coordinating body to streamline or guide the research agenda.

Of particular concern as well is the fostering of the community's participation. Some efforts have been made in the past to encourage this; thus far, these efforts have met with little success.

#### **Funding Sources**

The allocation of the national budget to research is very small, and even when earmarked it may be lost to competing interests. Some individuals apply for small research grants from the CCMRC for personal interest research. Other

main sources of funding include PAHO, the Overseas Development Agency (ODA), and local representatives of international pharmaceutical companies.

#### Constraints to Research Programme

The major constraints identified are:

The absence of a research coordinating mechanism or body; Inadequate funding; and Absence of a research culture.

# PLAN OF ACTION FOR INTRODUCING ENHR TO BARBADOS

ENHR is a strategy and a process to plan and carry out research that would lead to equity in health. It takes into consideration the existing manpower, infrastructure and financial situation to effect creative and productive problem-solving. Furthermore, it involves an interdisciplinary approach to the assessment of the problems and their solutions. Of necessity, it involves the constant interaction among policy makers, researchers and the community. It requires commitment at the highest level and an identifiable coordinating mechanism.

#### Strategy

- 1. It is recommended that the Ministry of Health and the Environment establish a Technical Committee by January 15, 1996, armed with the responsibility for implementing ENHR.
- The committee should comprise representatives of the Ministry of Health, the University of the West Indies as well as other secondary and tertiary health care institutions and non-government organisations involved in the delivery of health care.
- 3. A budgetary allocation of 0.1 % of the health budget is recommended for research.
- 4. By April 30, 1996, the committee will:

Review the Ministry's existing Development Plan and other policy directives and formulate a research priority listing.

Review and upgrade existing databases at health institutions, libraries and other research centres.

Review health systems data, including human resources, finance, infrastructure and training needs.

Set priority areas for research based on a consultative process which involves the interaction of policy makers, researchers and the community.

Identify researchers/research team for individual projects.

5. The committee will also:

Access information on current health trends.

Tap regional and international databases on a continuous basis.

Identify and mobilise financial resources from other local and regional funding agencies as soon as this is technically possible.

Access technical cooperation from regional and international bodies. Develop action plans for implementation with three months of research results.

Make information accessible to local and regional data banks and all stakeholders. Ensure the dissemination and sharing of information through the appropriate channels.

Examine existing research to effect incorporation into the ENHR process.

6. The working group would appreciate an early meeting with the Minister of Health and the Environment, Ministry officials and other relevant authorities, in an effort to gain a mandate for expediting this initiative. This meeting will provide the opportunity to discuss impressions of all the groups interested in health research. It would also provide a forum for the working group to further illustrate the importance of Essential National Health Research.

Progress reported by Barbados at the Follow-up Meeting, 19 April 1996, Jamaica.

The delegate from Barbados stated that anticipated progress in implementing the ENHR plan of action was not realised due to slowness in complying with necessary procedural matters. However, he assured the meeting that there was growing support for ENHR within the Ministry of Health and that a national ENHR workshop would be held in 1996.

### **CURAÇAO**

### Background and draft plan of action

The Netherlands Antilles consists of five islands with a population of 200,000. The largest island is Curaçao, which has a population of 140,000. There is a two-tier government, comprising the Central Government and the Local Governments on each island.

The Curaçao Health Study, its objectives and methodology, the involvement of health care professionals at an early stage, the dissemination of its results to health care professionals and institutions, decision makers, members of Parliament, political factions, other non-health government services, patient groups and the population at large, and the activities that have followed based on these results—transforming these into concrete actions: all form a foundation for institutionalising health research in a sustainable manner as a managerial tool for more informed decision-making.

At the same time, it is clear, however, that the different constituencies are still unfamiliar with this approach and process and with what their own role and contribution should be. There is a need for further sensitisation of different target groups for the concept, scope and mode of operation of ENHR, as well as for a discussion on how to organise this in a sustainable and effective manner.

This short-term action plan focused on three main areas: 1) Translating research outcomes into action; 2) Strengthening national commitment; 3) Networking.

#### 1. Translating research outcomes into action

The activities that have already been started up in this respect will be continued and intensified. The results of the Curaçao Health Study (CHS) will be further disseminated. One of the main objectives of the study was to make policy recommendations based on the results. These recommendations will be discussed with policy makers, health-care workers, Members of parliament, political factions, the Minister of Health and the Commissioner of Health, the Island Council, etc., as well as in the media, thus involving the population at large.

The Island Government of Curaçao has already given a mandate to the Steering Committee for the Restructuring of Health Care to make proposals for concrete action plans based on the results of the CHS. Short-term, national intervention/prevention programmes are suggested for diabetes, hypertension, and glaucoma. The Steering Committee has organised three multi-disciplinary working groups, including patient organisations, around each of these areas. Other recommendations will be followed up by the Steering Committee.

#### 2. Strengthening National Commitment

Several activities are being (should be) undertaken in this respect:

#### Promotion and advocacy of ENHR

A series of informal meetings/discussions with different target groups are ongoing, or need to be organised. The objective of these discussions is to introduce ENHR and to assess the needs, relevance and applicability of this strategy for the Netherlands Antilles.

In February of 1996, a symposium is planned in which, on the one hand, the CHS results and recommendations will be presented and the translation of these results into intervention programmes will be further discussed, and, on the other hand, the ENHR strategy for Curação and the Netherlands Antilles will be discussed, thereby also drawing from experiences elsewhere.

#### Mechanism for ENHR

Promotion and advocacy and the further development and implementation of an ENHR strategy in the Netherlands Antilles require a mechanism to steer the process. The Central Government of the Netherlands Antilles has already extended a mandate to ISOG 2000 for this purpose. ISOG 2000 should endeavour to establish a task force with the consensus and involvement of the different partners, and start working with a minimal agenda (i.e. overview of completed research, identification of research needs, collection of documentation, consultation with PAHO, etc.).

#### Capacity building

Capacity for health research in general, and for ENHR in particular, is limited. Moreover, it is crucial that the expertise already developed be not lost. One idea that could further be explored is the formation of a National Institute for health research. This also would form part of the agenda for the abovementioned task force. The role of such an institute, which should be linked to the University and include participation of all major partners in this endeavour (Ministry of Health, Medical & Public Health Service, University, NASKHO, ISOG 2000), should be to

- coordinate research activities;
- develop, organise and deliver training (HRD);
- "carry" ENHR:
- develop a national research programme ( priority setting );
- facilitate communication;
- facilitate and coordinate funding;
- concentrate research capacity.

#### Research activities

The CHS is a good example of scientifically sound and relevant research leading to decisions and actions. Other islands of the Netherlands Antilles as well as the Minister of Health have expressed their interest to expand this model throughout the Netherlands Antilles. Efforts are being undertaken to

formalise and implement this. Other countries in the region are also looking into the possibilities of using the CHS model.

#### 3. Networking

Considering the limited resources, both human and other resources, which holds true for the region as a whole, the establishment of a platform for real collaboration in ENHR in the Caribbean would seem an obvious and worthy goal to pursue. Such a platform could serve as a source for the development of ideas, for initialising joint research activities and for pooling of resources. Collaboration with European, American and international organisations and academic institutions is invaluable for the necessary backing and upgrading of local expertise. A joint proposal, entitled Caribbean Collaboration on Action Research in Health Care, has already been submitted for funding to the European Commission. The objectives of this project are:

- to further develop and standardise a health interview survey applicable to the Caribbean region and which can be used to monitor public health and evaluate the effects of intervention programmes and health-sector reforms;
- to generate comparable data on the health situation of Caribbean countries in order to identify common risk factors and to construct regional strategies for prevention and health promotion;
- to enhance research capacities and regional collaboration, thus improving the scientific and technical quality of action research in the region;
- to strengthen health policy and sustain the development of specific intervention programmes in the region.

The partners in this proposal are: the Northern Centre for Health Care Research from the Netherlands; the École de Santé Publique–Nancy, in France; the Health Plan and Evaluation Unit of the Servei Català de la Salut–Barcelona, Spain; COHRED; the Epidemiology & Research Unit of the Medical & Public Health Service of Curaçao; the Direktie Volksgezondheid Aruba; the Dienst Gezondheidszorg & Hygiene Bonaire; the Public Health Department of St. Maarten; the CCMRC; the Conceil d'Orientation de la Recherche INSERM in Martinique; the Faculty of Medical Sciences of the UWI in Barbados; the Ministry of Health & Social Security of Dominica; the Health Promotion Resource Centre in Jamaica; the Dirección General Sectorial de Saud Pública International of the Ministerio de Sanidad y Asistencia Social in Venezuela.

Progress reported by Curação at the Follow-up Meeting, 19 April 1996, Jamaica

#### 1. Translating research outcomes into action;

#### **Networking**

In February 1996, a workshop was organised to start up intervention working groups on diabetes mellitus, hypertension and glaucoma. The decision for doing this is based on the outcomes and recommendations of the Curaçao Health Study. The workshop was given by Professors Post (Community Medicine) and Van Den Heuvel (Medical Sociology), both of the Department of Health Sciences of the University of Groningen. The three working groups were indeed formed on a multidisciplinary basis, including patient groups. A coordinator was appointed in each group, and they have got under way and have met on a regular basis since then. Their task is to formulate and plan national intervention/prevention programmes and to outline strategies to ensure acceptability and actual implementation of these programmes in the field. The research data, as well as other relevant data and information, were made available to each group. They are being facilitated in administration and any other information needs that may arise. A member of the research team has been allocated to each group to ensure feedback of whatever research needs that may emerge. There is an overall coordinator who keeps in touch with the working-group coordinators and who keeps track of the activities. A plenary session to evaluate the progress is planned to take place within a month from now.

### 2. Strengthening national commitment

#### Promotion and advocacy of ENHR

In March 1996, ISOG 2000 (the Foundation for the promotion of Research & International Cooperation in Health Care) organised a symposium, using the Curaçao Health Study (CHS) as a starting point to move to a process of institutionalising health research in a systematic and sustainable manner as a managerial tool for more informed decision-making. COHRED and PAHO jointly helped sponsoring this meeting. COHRED actively participated in sharing global experiences and, specifically, in discussing the ENHR developments in the Philippines as an example.

#### **Mechanism for ENHR**

Following the symposium, a workshop was held, which was attended by some 40 participants, including a wide variety of health-care workers (clinical as well as non-clinical, government as well as private NGOs) and interested non-health members of the community. Our regional representative of PAHO was actively involved, as were the Commissioner of Health for Curação and the CMO of the Netherlands Antilles. Professor Nuyens and Dr. Lansang of COHRED assisted as resource persons. The participants of the workshop agreed that ENHR is a useful and valuable strategy for Curação and the Netherlands Antilles, and that it should be further developed and implemented. It was decided that ISOG 2000 should establish a task force to assess the way in which this could best be done, overcoming/resolving the obstacles and shortcomings that were noted (fragmentation of research initiatives, lack of research capacity, insufficient knowledge of, access to, and follow-up on results, absence of a mechanism for prioritisation in research). The task force would have to: 1) initiate and organise discussions between relevant groups concerning the development and implementation of an ENHR strategy; 2) formulate a plan of action containing the following elements: • strengthening the ties between policy makers, researchers, and community representatives; • development of research capacity and prioritisation in research; • creating a mechanism for carrying forward ENHR on a longterm basis.

The members of the task force would have to have a broad-based representation, and these members would in turn have the responsibility to inform and involve those they represent, and to canalise feedback.

The task force would have to present the outcomes of their endeavours to a wide audience by November 1996.

#### Research activities

In March 1996, the CMO of the Netherlands Antilles also organised a meeting with all heads of the Island Medical & Public Health Services. Among other issues, it was unanimously decided to extend the CHS to the other islands of the Netherlands Antilles. Meetings have been scheduled to take place to that end with the Windward Islands of the Netherlands Antilles by the end of April/early May.

# Networking

The joint proposal for concerted action for research in health care in the Caribbean submitted for funding to the European Commission has not been approved. Nonetheless, Trinidad, for example, has expressed interest in using the CJWS model, and we will hopefully jointly further explore the possibilities.

#### **JAMAICA**

#### Background

Jamaica has a population of approximately 2.5 million. The infant mortality rate is 24/1,000, and life expectancy is 70 years. The adult literacy is approximately 80%, with the per capita income being US\$1,200.

#### Health Research Facilities and Policies

There are several research centres in Jamaica. These include the University of the West Indies (UWI), in particular the Tropical Metabolism Research Unit (TMRU) and the Institute of Social and Economic Research (ISER); the Ministry of Health (MOH), the Medical Research Council (Sickle Cell Unit), the Caribbean Food and Nutrition Institute (CFNI), the Planning Institute of Jamaica (PIOJ), and the Statistical Institute of Jamaica (STATIN).

Some of Jamaica's health research policies have been highlighted in the 1985 Epic workshop and in the current Health Plan of the MOH. Health Research Priorities have not been specifically defined, but they coincide with those of the Caribbean Cooperation in Health initiative agreed upon by the Caribbean Health Ministers in 1986. These include:

Human resource development

Chronic non-communicable diseases and accidents

Environmental protection, including vector control

Strengthening health systems

Food and nutrition

Maternal and child health and population activities

**AIDS** 

The Health priorities can also be examined by age group:

<u>Children under 5 years</u>. There has been some operational and basic research in perinatal conditions as well as in malnutrition and EPI.

<u>School children</u>. A survey has been conducted on dental health and the advent of fluoridation as well as on anaemia. There have been interventions in the areas of visual defects, hunger and malnutrition. However, teenage pregnancy remains a problem.

<u>Young adults</u>. There were operational research studies investigating sexually transmitted diseases, family planning and maternal health as well as surveys on drug abuse and lifestyles.

<u>Adults</u>. The principal areas of concern include chronic non-communicable diseases, mental health, occupational health, and the elderly.

A research gap has been identified in the following areas:

The concept of socialisation, including values and attitudes

Sexual behaviour

Lifestyle changes.

Areas of concern in Health Services research include:

Organisation

Cost

Management

Quality control

Evaluation.

In addition, a role has been identified for the social services and research in:

Policy analysis

Clinical epidemiology

Health systems research

Evaluation

Protocol preparation

Ethical review.

#### **Problems**

- 1. Lack of co-ordination between various Research Units.
- 2. Lack of an inventory of current research.
- 3. Communication, in particular with the public, in transforming the data into action, and with major stake players.
- 4. There is also a need for a research data bank.
- 5. Funding.
- 6. There is a need for an overall strategic plan for research.
- 7. More basic research is needed along with a mix with operational research.

#### PLAN OF ACTION FOR INTRODUCING ENHR TO JAMAICA

Earlier working groups have identified three main challenges to the promotion of the idea of Essential National Health Research. These include the perception of health research, the fragmentation of current research efforts and the predominance of biomedical research. The groups felt that there was a need for a clear definition of "health research" through:

written policies/plans;

budgetary allocations;

clarification of roles and responsibilities of key players;

justification to support the need for specific studies.

The team supported the concept of ENHR as an appropriate means through which these issues can be resolved. ENHR was seen as the way forward to support the efficient and effective use of resources to promote meaningful research. To achieve this goal, the team focused on the stages/steps which will be necessary to move the process along.

In the short term, it was felt that there is a need to appoint a Task Force to examine ways and means of establishing a coordinating body. This body will

then have a mandate to deal specifically with the identified problems which militate against a national agenda for health research.

#### **Short Term**

There will be the preparation of an inventory of existing Health Research.

- Step 1. To obtain a commitment from the Ministry of Health to support the establishment of a task force and to fund initial efforts to this end.
- Step 2. With support from personnel at the PIOJ and ISER, an inventory of existing research is to be compiled.
- Step 3. This inventory of research will provide additional information on **who** is doing **what** research and from **which** institutions and agencies; areas of interest; and research gaps. This information will then be disseminated to the key researchers/institutions.
- Step 4. This small group will discuss the information derived from the inventory of research and consolidate, add to, or clarify, information previously disseminated. Further deliberation will address issues related to research capacity, the research gaps and identification of other interest groups who are engaged in research, as well as the sources of funding for research.

The outcome of this meeting should help to identify the participants of a national meeting aimed at establishing a coordinating body/mechanism to guide health research thereafter.

The need to involve as many constituencies at this meeting is acknowledged. However, the strategy to achieve this broad base of participation is not an obvious one, given the experience of earlier attempts. Perhaps this issue will require further research, since it is acknowledged that the bottom-up rather than the top-down approach to planning/decision-making is more likely to produce implementable programmes. Thus a strategy must be identified to broaden the base of participation.

There is a need for the media to be represented at every step and stage of the process — from short-term to long-term planning — and they must be given a specific role in the coordination process as it relates to information dissemination.

This Task Force will also examine ways in which a coordinating body can effectively carry out monitoring and evaluative activities. The specific objectives of this body are:

- 1. To create a framework for facilitating effective coordination.
- 2. To identify gaps in information and manpower.
- 3. To identify a method of dissemination of information.
- 4. To examine methods of involving the community/users.
- 5. To facilitate evaluation.

This phase is projected to cover a period of six months; the small working group will convene in February 1996, and the national meeting will be held in May/June 1996.

#### **Medium Term**

This phase will cover the establishment of the coordinating body to promote the concepts and guide the further process towards institutionalising the **ESSENTIAL NATIONAL HEALTH RESEARCH** strategy.

#### **Funding Sources**

Funding to facilitate the process will be sought from COHRED, CCMRC, and the Government of Jamaica (GOJ).

#### **Research Working Group Collaborators**

The institutions identified as potential collaborators are:

Ministry of Health, which will serve as the coordinator

**PIOJ** 

University of the West Indies (UWI)

Scientific Research Council

Statistical Institute of Jamaica (STATIN)

CFNI / Pan American Health Organization (PAHO)

Others to be co-opted when identified.

The secretariat will comprise technical staff of the Policy Development Unit of the PIOJ and the ISER.

#### Possible Collaborators for the Forum

In addition to the above-named, the forum will include representatives from the

Private Sector Organisation of Jamaica

**Press Association** 

**Medical Associations** 

Association of Women's Organizations (AWOJA)

Political Directorate

Senior Directorate of the Ministry of Health.

#### Summary of Work Plan — Jamaica

Goal	Objectives	Strategies	Collaborators	Funding Sources	Time Frame
To develop a strategy and an action plan for setting and acting on priorities with identified interest groups	1. To establish an institutional framework to coordinate health research  2. To identify existing research and determine research capacity, required research needs and skills  3. To identify research interests and gaps  4. To develop mechanisms for dissemination of research	Establish Task Force Administration support: PIOJ & ISER. Role of this force; identify and establish inventory of research (institution, capacity, interest, past & current activities & relevance to existing health priorities & financial sources	PIOJ/ UWI/MOH	COHRED, CCMRC, GOJ	STEP 2: small group meeting, February 1996 STEP 3: National Forum; May/June 1996

# Progress reported by Jamaica at the Follow-up Meeting, 19 April 1996, Jamaica

- The Jamaican team met in January 1996, and received commitment from PIOJ & ISER
  to prepare a questionnaire for institutions and researchers engaged in health research.
  These institutions include those at the University and the Scientific Research Council,
  the government ministries and international agencies.
- 2. Twenty-two departments/researchers were identified at UWI. All heads of institutions/researchers were contacted at UWI. Twelve completed questionnaires were returned. However, additional information is required from four heads of departments. Letters of introduction were sent to all heads of departments in the Ministry of Health. The respondents were receptive to ENHR, but many expressed the hope that this was not "just more hot air." Two completed questionnaires were received.
- 3. Data entry and data analysis are progressing slowly because the researchers are employed full-time. A research assistant is needed very quickly to ensure that all data collection and analysis are completed before September.
- 4. The next meeting of the Jamaican team is set for May 10, 1996.
- 5. The national forum is set for September 1996.

The meeting agreed that Jamaica should submit to CCMRC a request for funds for the personnel required to complete the data entry and analysis so that results will be available for the National Forum in September 1996.

#### TRINIDAD AND TOBAGO

#### Background

Trinidad and Tobago is a twin island republic with a population of 1.2 million people, 50,000 of whom live on the island of Tobago. It is an English-speaking country, although the inhabitants originally came from many continents and spoke many different languages. Therein lies the most challenging problem as well as the richest resource. 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

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. This is reflected in the attention that this age group's health problems receive, such as adolescent pregnancy, STDs, and injury. However, this bulge will move to the 35-45 age group in 20 years' time, and the problems then will reflect those of a more adult population. In twenty years' time too, the population over 65 will increase by 60%, and this will also cause higher numbers of persons with disability and mental illness.

#### 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, and the number is even higher if the population under 65 is examined. There are reports that functional literacy is high, and this may have resulted from the quality of the education, especially at primary level. In the recent National Health Survey, educational attainment was the only socio-economic variable that was consistently related to health status.

#### **Economic Aspects**

Economic indicators appear to be stabilising, but in terms of the health sector the effect is still relatively negative. It is estimated that US\$167 million are spent on health, representing about 5% of the GDP. Fifty per cent of this is 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 spends 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% is 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.

It is difficult to assess how much is spent on health promotion. There is no top slicing of funding. Neither is there local health system funding for health promotion. Most of the funds used are raised from international donors and from local private sector funds.

#### **Health Problems**

The major health problems are heart disease and stroke, cancer, diabetes, injury, and AIDS. Communicable diseases are much less, but have not disappeared. Pneumonia deaths among the elderly and in the first year of life still account for significant numbers of avoidable deaths. ARIs, skin infections, and diarrhoea are still the most reported reasons for visiting child-health clinics. The number one environmental problem for the public is the mosquito nuisance (in the National Health Survey (NHS) of 1995, 79% felt that this problem affected the health of their household). Tuberculosis is an anticipated threat, but age-specific rates are still static. Mental illness is a significant cause of morbidity. In a recent survey (NHS 1995), 20% of adults appeared to be at risk. Injury (accidents, homicides, and suicides) rates are high.

Information on health determinants is generally missing, and that affects programmes. There have been many prevalence studies (KAPS, population studies), but there has been a lack of more analytic studies. It is not possible to design effective interventions with the current disease profile without such studies. It is also clear that Health Systems Research will need much more emphasis. However, this depends on prior identification of needs.

#### Health System

The health system in Trinidad and Tobago is being reformed. The final structure will be a decentralised 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.

#### **Mobilisation of Resources**

There is no formal mechanism for mobilising resources. However, there are indications that the environment is now encouraging such an approach. Both PAHO and the Caribbean Epidemiology Centre (CAREC) have held gatherings of donors. UNICEF, CCMRC, and the ODA, have policies which promote certain types of research. What appears to be missing is a coordinating mechanism which would identify pressing research priorities without suppressing individual effort or reducing funding.

#### **National Research Priorities**

It is necessary to formulate research priorities arising out of the necessity to answer questions by Ministries and other organisations. However, for some time, there has been a tension between the Ministry of Health's needs and those articulated by non-health organisations, or by independent researchers. This is one of many reasons why it has been recommended that the Ministry strengthen its capability to conduct its own research based on health needs assessment.

The different kinds of research needed include:

- <u>Descriptive studies</u>: Health needs assessments in order to allocate resources and make choices.
- <u>Analytic studies</u>: Why, what are the determinants of health, which factors would be beneficial to tackle?
- <u>Evaluations:</u> Which interventions work, are cost effective, and which policies should be recommended.

#### Coordinating National Health Research

Research committees have been dominated by a single profession. In the 1980s, an attempt was made to establish a national body, the National Institute for Higher Education and Research in Science and Technology (NIHERSI). This organisation has made a great contribution to education, but it does not appear to have been successful in terms of stimulating essential health research. A new report has recently been issued which indicated that it may be beneficial to establish a National Health Research Committee which is represented on the NIHERST body. There is a need to establish a database (MEDCAR produced by the Medical Library of the UWI is a start, but it is neither current nor comprehensive).

### **Health Policy Development Process**

The health system reform has produced an opportunity for generating health research priorities. A directorate of Health Policy, Planning and Health Promotion has been established, which will focus on epidemiology and health information, policy development, and health promotion. Decentralised 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. Already, there have been two activities along these lines, one a document entitled Health of Trinidad and Tobago, 1995, which suggested priorities and the justification for them, and, secondly, a National Health Survey, which attempted to collect baseline data on some of these priorities.

#### **Health Research Inventory**

Although this review is incomplete, it is intended to show that some essential health research is being conducted by organisations and by independent researchers.

#### Ministry of Health

Situation Analysis, 1989

National Health Survey, 1995 Ability and Willingness to Pay, 1995 Tuberculosis sero-survey

#### UNICEF

Low birth weight study, 1990 Children in Difficult Circumstances, 1993

#### **PAHO**

KAP (Chronic Diseases), 1990 Cholera KAP, 1991 Injury, 1992

#### **Social Services**

Disability, Family

#### **Overseas Development Administration, UK**

Health Services Research & Training in Chronic Non-communicable Diseases In the Caribbean

#### National Institutes of Health (NIH), USA

AIDS, HTLV I

#### **Central Statistical Office (CSO)**

Survey of Living Conditions

#### **National AIDS Programme (NAP)**

AIDS knowledge in young people

#### **Family Planning Association (FPA)**

Demographic Health Survey

#### Plymouth-Bethesda Study

Lifestyle factors, mortality from CHD, LVH

### St James Cardiovascular Study

## Drug use in school children

**UWI** — Much unpublished data and so unknown to decision makers.

# PLAN OF ACTION FOR INTRODUCING ENHR TO TRINIDAD AND TOBAGO

The team members used a strategic planning framework to deliberate on the vision, objectives and action plan for ENHR in Trinidad and Tobago. The team

rationalised the development of ENHR as a strategy, based on five main factors:

- 1. The need for central coordination and leadership to optimise the use of existing resources.
- 2. The opportunity provided by the Health Reform process can be used to institutionalise ENHR.
- 3. The need to generate research funding locally.
- 4. The need to provide direction for donors.
- 5. The research needs of decision makers vs. researchers.

The team acknowledged that there were factors (strengths) existing both within the country and the Ministry of Health that had the potential to facilitate the establishment of the ENHR strategy in Trinidad and Tobago. Among the strengths identified were:

- Several interested groups: the evidence suggests that there is a number of research activities currently in progress. It was felt that the pooling of resources and efforts may make for better, more coordinated use of the resources, including human resources.
- Health system reform in progress: this was seen as positive to the extent that it provided a golden opportunity for the Ministry of Health to institutionalise the concept and approach to coordinated and focused research efforts in the form of ENHR.
- The Ministry of Health and the Regional Health Authorities (RHAS) are expected to negotiate based on health needs assessment. The methods of health needs assessment would offer a more scientific basis on which to base research priorities.
- A great deal of data are already available: there is room for improving the quality of those data and for transforming the data into usable information.
- Institutional framework: among the agencies located in Trinidad and Tobago with an interest in conducting research are: CAREC, CCMRC, CSO, UWI, NIHERST.

It was generally agreed that the ENHR should have a central coordinating body. A number of options for the location of this body were explored, with the team considering three possibilities: location within the Ministry of Health (MOH); a completely independent statutory body; or location within the UWI.

It was felt that the location within the MOH was advantageous to the extent that it was more likely to ensure the support of decision makers, and it would be relatively easier to establish. On the other hand, the disadvantages of location outside of the Ministry included problems with ownership; the possibility of isolation; and overhead cost implications.

A vision for ENHR was established which included the following aspects:

To improve the quality of life;

To improve the research environment;

To achieve equity in development;

To translate information into public health action;

To strengthen the health needs assessment process in defining research priorities.

The objectives are:

To establish a database: this would include research information from all sources, and information on the people involved in health research;

To improve the quality of existing data;

To identify essential research priorities;

To stimulate the demand for information by decision makers;

To advocate that policy development be based on information;

To establish a research policy framework.

# **Proposed Structure**

#### **CENTRAL**

Director of Research (With support team)

Representatives from:

Government

Ministry of Health (MOH)
Policy & Planning
Epidemiology
Health Promotion
Regional Health Needs Assessment units

Ministry of Social Development

Central Statistical Office (CSO)

National institute for Higher Education, Research Science and Technology (NIHERST)

UWI

Faculty of Medical Sciences Faculty of Social Sciences ISER

**CCMRC** 

Caribbean Epidemiology Centre (CAREC)

**Private Sector** 

Non-Government Organisations (NGOs).

#### **REGIONAL**

Health Needs Assessment Staff.

NGOs, community representatives, service providers, social services.

### Proposed Strategy

- To meet with the Chief Medical Officer and the Manager of Policy, Planning and Health Promotion Unit, MOH, in order to acquaint them with the concepts of ENHR and to seek their commitment to the strategy.
- To invite CCMRC to participate.
- To arrange a series of meetings with representatives from the research community to get a commitment to concept.
- To conduct a national ENHR workshop with all potential stakeholders to draft a strategic plan for establishment and implementation of ENHR in Trinidad & Tobago.
- To strengthen the Research Unit within the MOH.
- To establish a Central Coordinating Body within the MOH as well as to establish Regional Research Units/Committees.

# Progress reported by Trinidad & Tobago at the Follow-up Meeting, 19 April 1996, Jamaica.

The Country Team of Trinidad and Tobago met with and reported on the Jamaica Workshop to the Chief Medical Officer and other key officials at the Ministry of Health, Trinidad and Tobago. There was full acceptance and support for the convening of a National Workshop on ENHR, 26–27 April 1996, in Trinidad. The Minister of Health, the Hon. Dr Hamza Rafeeq agreed to give the Feature Address, and invitations have been issued to a wide range of representatives from Government, the University of the West Indies, NGOs, and other interested groups.

The meeting suggested that an invitation should be issued to Barbados and Jamaica to each send an observer to the ENHR Workshop in Trinidad, as these two countries would be also convening National ENHR Workshops during the coming months. This suggestion was readily accepted by the Trinidad & Tobago delegates, and CCMRC was requested to arrange for the visitors' attendance.

# ANNEX 1: WORKSHOP PROGRAMME

Sunday, 5 November 1995	Official Opening Ceremony
Monday, 6 November 1995	
09:00 – 09:30 a.m.	Introductory Session, Dr D. Picou
	<ul> <li>Background of Meeting</li> <li>Objectives and Expected         <ul> <li>Outcomes of the Meeting</li> </ul> </li> <li>Adoption of Draft Agenda</li> </ul>
09:30 – 10:30 a.m.	Essential National Health Research : Concepts and Practice
	Dr P. Figueroa and Dr Y. Nuyens
10:30 – 10:50 a.m.	Coffee Break
10:50 – 00:30 p.m.	The Current Status of Health Research
	Country Presentations:
	Barbados
	Curaçao Jamaica
40.00.00	Trinidad and Tobago
12:30 – 02:00 p.m.	Lunch
02:00 – 03:30 p.m.	Country Experiences with Health Research Priority Setting
	Critical Review of Country Experiences     (Dr M. Mugambi, Kenya)
	The Case of South Africa     (Dr S. Tollman, South Africa)
	The Case of Thailand     (Dr C. Sitthi-amorn, Thailand)
03:30 – 04:00 p.m.	Coffee Break
04:00 – 05:30 p.m.	Plenary Discussion and Conclusions of the day, Drs D. Picou and P. Figueroa
Tuesday, 7 November 1995	
09:00 – 10:30 a.m.	Introduction to Group Work on Health Research Priority Setting (Plenary Session); resource persons
10:30 – 00:30 p.m.	Country Working Groups to develop strategy and action plans for health research priority setting in their countries

# Workshop Programme cont'd

00:30 – 02:00 p.m.	Lunch	
02:00 – 03:30 p.m.	Country Working Groups Continued	
03:30 – 04:00 p.m.	Coffee Break	
04:00 – 04:30 p.m.	Plenary Session to clarify outstanding questions and issues	
04:30 – 05:30 p.m.	Country Working Groups finalise and prepare Plans of Action for presentation	
Wednesday, 8 November 1995		
09:00 – 10:30 a.m.	Presentation and Discussion of Country Plans of Action	
	Barbados	
	<ul><li>Curaçao</li><li>Jamaica</li></ul>	
	Trinidad and Tobago	
10:30 – 10:50 a.m.	Coffee Break	
10:50 – 12.00 a.m.	Discussion on Regional ENHR Collaborative Activities	
12:00 – 00:30 p.m.	Closing of Workshop	

# ANNEX 2: LIST OF PARTICIPANTS AND RESOURCE PERSONS

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List of Participants and Resource Persons cont'd

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# Annex 2: List of Participants and Resource Persons cont'd

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# Annex 2: List of Participants and Resource Persons cont'd

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