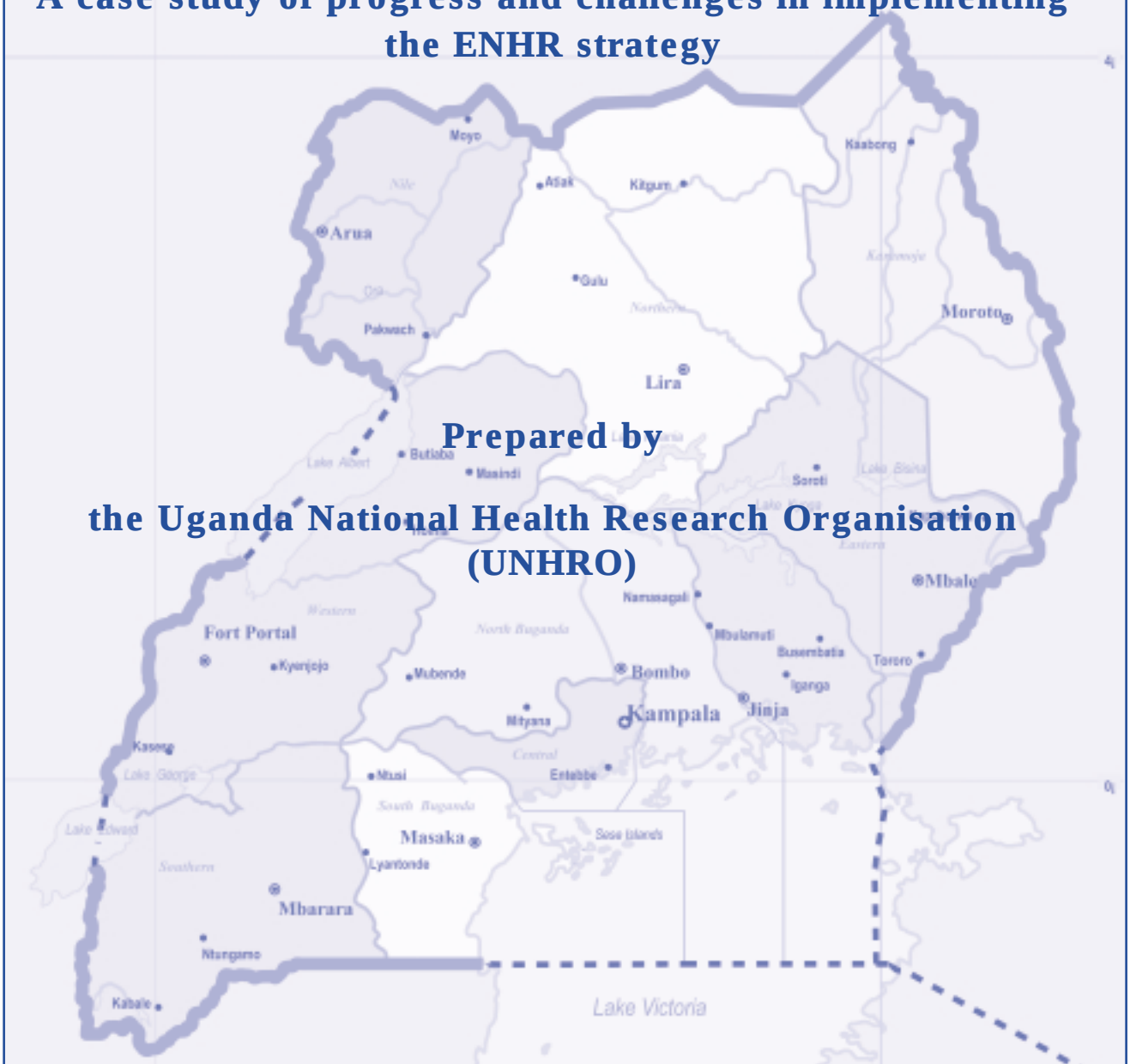
Essential National Health Research in Uganda

A case study of progress and challenges in implementing the ENHR strategy



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Abbreviations

AMREF	African Medical Research Foundation
CEU	Clinical Epidemiological Unit
CHRD	Commission on Health Research for Development
COHRED	Council on Health Research for Development
ENHR	Essential National Health Research
IHPP	International Health Policy Programme
MCH	Mother and Child Health
MOH	Ministry of Health
NRM	National Resistance Movement
NGO	Non-Governmental Organisation
PHC	Primary Health Care
UNHRO	Uganda National Health Research Organisation
UNCST	Uganda National Committee for Science and Technology
UNICEF	United Nations Childrens Fund
WHO	World Health Organization

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Chapter One: Introduction and background to health research in Uganda

1.1 Introduction to ENHR in Uganda

Uganda adopted the Essential National Health Research (ENHR) strategy in February 1991. Since then a number of activities have been organised. Following the initial ENHR Workshop, an Ad hoc Committee developed mechanisms for research priority-setting, which were followed by the development of a national ENHR plan. The first plan (1993-1996) was launched in May 1993 and the second (1997-2001) is now in progress.

This monograph describes and analyses the various activities that have been undertaken since the adoption of the ENHR concept. These include promoting ENHR at the community and district levels and we hope the experiences described below will enhance our efforts to reach those target areas. Other countries implementing the ENHR strategy may also benefit from these experiences. The monograph is evidence of the degree to which we have benefited from the support of the Government of Uganda and of various donors. We believe the analysis presented will be useful in enabling both the Government and donors to make the best use of their resources.

1.2 State of health research in Uganda: review of past achievements and deficiencies

Since the 1930s the Medical School at Makerere University and its associated teaching hospital at Mulago have been the centre of medical research in the country. Great contributions were made, particularly in the areas of cardiology, gastro-enterology, malnutrition and cancer[1], where the emphasis was mainly on clinical research. These contributions gave high visibility to Makerere University internationally, and it was the centre of excellence for medical research in Africa. Although Makerere Medical School was a national institution, there were few contacts between the researchers and officials of the Ministry of Health (MOH). Research findings reached the Ministry by a trickle-down effect rather than through active dialogue between researchers and policy makers. The community benefited from the same inadequate process.

On the Mulago Hill next to the Medical School there was a well-developed Research Unit on Malnutrition in Children. This unit belonged to the British Medical Research Council and did not report to the MOH. The Unit was closed down when President Idi Amin expelled Asians from Uganda in 1973. The premises were later renovated and now houses the Child Health and Development Centre.

During colonial days, a number of research institutes existed in East Africa. In Uganda there were the Virus Research Institute in Entebbe and the Trypanosomiasis Research Organisation in Tororo. When the East African countries (Kenya, Uganda and Tanzania) gained independence from Britain in the early 1960s, a move was made to form the East African Community and these research institutes belonged to the Community. The East African Medical Research Council and its secretariat based in Arusha were responsible for running these institutes. Research priorities were determined by the institutes and approved by the Council. The Institutes reported research findings to the Council but there was no direct link between the research institutes and the ministries of health. It took a long time, therefore, for the research findings to trickle down to health managers in the countries.

When the East African Community collapsed in 1977, the research institutes were returned to the parent countries. In the case of Uganda, the Virus Research Institute and Trypanosomiasis Research Organisation were placed under the MOH. But in the late 1960s, well before the collapse of the Community, Uganda recognised the need to coordinate research in the country, and subsequently established the National Research Council in 1970. The Council had six committees, including the Medical and Veterinary Committee. The Council was not a statutory body, but a department of the Ministry of Planning and Economic Development. It did not have jurisdiction over the research institutes in the East African Community and did not take them over after the breakdown of the Community. Neither the National Research Council nor its Medical and Veterinary Committee was directly linked to the MOH[2]. The Committee used medical experts to draw up research priorities based on what they perceived to be the burden of disease. The research priorities in medicine of the National Research Council are shown in Table 1-1. It should be noted that the research priorities were medical and did not cover the health sector as a whole. They also tended to be clinically based. The coordinating function of the National Research Council was not effective. The Medical and Veterinary Committee met monthly and approved research proposals, but these were not coordinated and were not relevant to the needs of policy makers and health managers. Most of the research funding came from outside Uganda.

Table 1-1 National Research Council priority ratings for medical research[3]

A. Essential research:

- **Liver Disease:**
  - *Serum hepatitis:* immunology
  - *Cirrhosis of the liver*
- **Gastro-enterological disease**, including hernia, volvulus; cirrhosis and malabsorption
- **Haematology**
- **Infectious disease**
- **Cancer:**
  - *Burkitt's lymphoma:* possible virus aetiology
  - Other *Lymphomas*
  - *Hepatocelullar carcinoma*
  - *Kaposi's sarcoma*
  - *Malignant melanoma*
  - *Chorion carcinoma*
  - *Carcinoma of the penis*
  - *Carcinoma of cervix*
  - *Cancer of the oesophagus*
  - *Leukaemia*
  - *Ovarian tumours*
  - *Endocrine tumours*
- **Asthma**
- **Tuberculosis**
- **Tropical** (endemic) **disease:**
  - *Malaria*
  - *Schistosomiasis*
  - *Sickle cell diseases and other haemoglobinopathies*
  - *Malnutrition*
  - *Gastro-intestinal parasitic disease*
  - *Buruli ulcer*
- **Survey of psychiatric syndromes**
- **Maternal and infant mortality**
- **Urinary tract diseases**, including *urethral stricture*
- **Cardiomyopathies**
- **Tropical viral fever:**
  - *Arbovirus studies:* Isolation and identification of arboviruses, which are pathogenic to humans, and the study of their animal hosts and vectors, serological surveys in humans and animals, including investigation of immunity to yellow fever in humans, monkeys, bush-babies, etc.
  - *Entomological studies:* Surveys of known or potential vectors (mosquitoes and ticks) of arboviruses with special reference to associations with reservoir and amplifier systems; study of insect species other than mosquitoes potentially important as vectors
  - *Vertebrate virus Zoonoses:* Studies of mammals and birds, which are potential disseminators of viruses pathogenic to humans
  - *Respiratory virus survey*
  - *Viruses other than arboviruses*, respiratory and enteroviruses causing disease in humans
- **Sero-epidemiology of rickettsial infections**

B. Required research:

- **Systematic and cutaneous Nematode infections**, including onchocerciasis and filariasis
- **Measles:** sero-epidemiology of rubella
- **Investigation of cytomegalovirus infections**
- **Relation of coxsackie B virus infections** to suppurative parotitis and pyomyositis and certain other commonly occurring local diseases
- **Trypanosomiasis**
- **Sterility and infertility**

C. Desirable research:

- **Poliomyelitis:**
  - Study of the characteristics of the three polio viruses and other enteroviruses causing human paralysis in East Africa
  - Detection and characterisation of enteroviruses in young children and the efficacy of oral poliovirus vaccines
- **Neurological disease**
- **Venereal diseases**
- **Mycoses**
- **Myiasis**
- **Collagen diseases**

1.3 Origins of multidisciplinary cooperation

To understand the development of ENHR in Uganda it is important to appreciate the occasions on which researchers of different disciplines came together, and induced policy makers and researchers to exchange ideas on health research. This section illustrates how the ENHR spirit existed in Uganda before the strategy was formally adopted in 1990. There were five main occasions that brought people together.

Review of the medical education curriculum

Makerere Medical School was established in 1922 with a curriculum that was basically curative and hospital-oriented. From 1983, the Faculty became increasingly concerned about the need to develop a more relevant and more community-oriented curriculum. To do so, it was necessary to involve the following stakeholders in the review process:

- members and students of the Faculty of Medicine;
- practising physicians within the communities;
- community leaders;
- Faculty of Social Sciences;
- Department of Psychology in the Faculty of Education;
- Training Division of the MOH;
- National Curriculum Development Centre, which is linked to the Ministry of Education;
- Centre for Continuing Medical Education;
- professional organisations, including Uganda Medical Association and Uganda Nurses and Midwives Association;
- Uganda Medical Practitioners and Dental Surgeons Council;
- United Nations Agencies — WHO and UNICEF;
- NGOs, such as AMREF.

During the curriculum development exercise, these various groups opened up a dialogue and developed a better understanding of each other. It is important to appreciate that this was a multidisciplinary and cross-sectoral exercise. Communities and health care providers were also consulted, and the participation of university teachers, policy makers and communities was like sowing the seeds of ENHR that were to sprout a few years later. Makerere Medical School became a member of the International Network of Community-Oriented Education Institutions for Health Sciences in 1989. A year later the network was to play a major role in the advocacy of ENHR in Uganda.

Child Health and Development Centre

In 1985 the Faculty of Medicine established the Child Health and Development Centre to implement the UNICEF Child Survival Strategy. It is a multidisciplinary centre with the participation of the Faculties of Social Sciences, Agriculture and Continuing Education, as well as the Makerere Institute of Social Research. The objectives of the Centre were to:

- identify and define the University's role in public health care
- coordinate public health activities of the different departments in the Faculty of Medicine
- promote and coordinate the teaching of PHC/MCH in the undergraduate curriculum

- establish a model clinic for comprehensive child health care
- facilitate and improve service, teaching and research
- promote a multidisciplinary approach to PHC in the University
- serve as a resource for PHC information
- support government policy initiatives on PHC by responding to educational needs of government staff by providing consultations and expertise, and maintaining a dialogue between University and Government
- identify local and international agencies undertaking PHC development projects and promote collaboration between them
- generate publicity in the press, radio, television and public meetings that will encourage community dialogue and involvement in PHC strategies.

The Child Health and Development centre became closely associated with the UNICEF Child Health and Development Centre in Florence (Italy), and was a member of the International Network for Capacity Building for Child Survival and Development. It remains a multidisciplinary research unit in the Faculty of Medicine and does mainly community-based research in collaboration with government departments, NGOs, and research organisations from overseas.

Clinical Epidemiology Unit (CEU)

In 1986, the Dean of Makerere Medical School requested that the School be included in the International Clinical Epidemiology Network, supported by the Rockefeller Foundation. In September 1987, eight young faculty members were interviewed by a team from the Foundation and two of them were accepted for training. When they returned, they formed the basis for the Clinical Epidemiology Unit in the School. The Unit is now multidisciplinary, consisting of physicians, social scientists, health economists and statisticians. In the early years of its existence the Unit concentrated its efforts on clinical problems, but in recent years it has also tackled community-oriented research problems.

Health Policy Analysis and Development (HPAD) Group

Uganda was one of the first countries to be included in the International Health Policy Programme (IHPP) in the late 1980s. A Health Policy Analysis and Development Group was established to undertake research in the area of health policy. The operations of the Group had a narrow base in the MOH, and have suffered certain management and implementation teething troubles. The problems triggered consultations between the MOH, CEU and IHPP (Washington). The Health Policy Analysis and Development Group was restructured to include researchers from CEU and MOH, and the Group is now functioning well. Later it was administratively linked with the UNCST. This is an example of how collaboration between different stakeholders has made it possible to operate a research programme. The programme has now been discontinued, but has left Uganda with a strong multidisciplinary team for health policy analysis.

Seminar on Beyond Crisis: Social development in Uganda

In 1985, Dodge and Weibe published a book describing the breakdown of health services in Uganda during the period 1971-1985[1]. A few months after the National Resistance Movement took over the government in January 1986, the UNICEF Office in Kampala organised a seminar on "Beyond Crisis". Participants were drawn from different faculties and sectors. They exchanged experiences and made suggestions about how to overcome the crisis described by Dodge and Weibe. The seminar provided an opportunity for researchers in different sectors to advise the new Government on what steps to be taken. In his opening address to the seminar, the Minister of Health stated:

The NRM Government has inherited a health system that has not only been stagnant but also rapidly decaying. The health of our people must be improved if economic progress and social justice are to be attained. The Government is committed to promote health and prevent disease by popular/community participation, guided by correct political leadership. Although the constraints of limited financial resources cannot be overcome overnight, rational utilisation of what is available should produce a tangible impact on the well-being of the people.

Participants in the seminar made the following major recommendations:

- democratisation of decision-making
- special attention to vulnerable groups, for example women, children and the handicapped
- communities should be allowed to pay for services, such as drugs and water protection where possible, to ensure sustainability.

1.4 Review of the health policy

In its efforts to rehabilitate the health sector, the MOH set up a Health Policy Review Commission in 1987 under the chairmanship of Professor Raphael Owor. The work of the Commission involved consultations with policy makers and decision-makers of relevant ministries, district health teams, professional organisations, communities and individuals. The process was similar to essential national health research. In the specific areas of health research, the Commission recommended that a mechanism be established to coordinate health research in the country as a whole. The mechanism was to work closely with the MOH.

1.5 Establishment of the Uganda National Council for Science and Technology (UNCST)

The National Resistance Council (the Parliament) established the Uganda National Council for Science and Technology in 1990[4] . The Council has direct links to the Ministry of Finance and Economic Planning. Its functions are briefly as follows:

- to advise and coordinate the formulation of explicit national policy in all fields of science and technology
- to assist in the promotion and development of indigenous science and technology planning
- to act as a clearing house for information on research
- to disseminate research findings.

One of the specialised committees of the Council is the Medical Sciences Committee, which focuses mainly on coordination of health research in the country. The Committee does not have its own secretariat and has not been very effective, not least because its members meet infrequently.

Chapter Two: The adoption of ENHR in Uganda

2.1 Recommendations of the Commission on Health Research for Development

The Commission on Health Research for Development (CHRD) was established in 1987 to recommend ways in which research might improve the health and well-being of people in the developing world. Following a wide-ranging consultation and analysis, the Commission released its first report in February 1990[5]. One of its recommendations was that each country, no matter how poor, should have a health research base, enabling it to understand its own problems. The Commission advocated that the process of setting priorities for national health research be inclusive and involve scientists, decision-makers and representatives of the people as equal partners. This was the beginning of the concept of Essential National Health Research (ENHR).

ENHR conveys three basic messages to countries in the process or about to undertake a programme of health research. These are: put country priorities first; work towards equity in health care; and concentrate on translating research into policy and action. The concept is based on three basic messages and seven strategic elements for implementing ENHR, namely promotion and advocacy, ENHR mechanism, priority setting, capacity building, networking, financing and evaluation. Eventually the elements evolved into what has become known as the ENHR technology consisting of nine competencies, namely the seven strategic elements plus two new ones: community participation and translating research into policy and action.

Stimulated by the ENHR concept, the Uganda MOH appointed a Working Group in August 1990 to organise a national ENHR workshop. The Group consisted of Professor Raphael Owor, Chairperson (former Dean of Faculty of Medicine, Makerere Medical School); Dr. J.G.S. Makumbi (Deputy of Medical Services, later Minister of Health); Dr. J.H. Kyabaggu (Deputy Director of Medical Services, now Director of Health Services); Dr. E. Sempala (Director, Uganda Virus Research Institute); and Dr. P.Y. Kadama (Health Planner, MOH, Secretary). In November 1990, Dr. Owor and Dr. Kadama participated in the International ENHR Workshop in Pattaya, Thailand, where they shared experiences with ten other developing countries. This greatly enhanced their understanding of the ENHR strategy, with its multidisciplinary and cross-sectoral approach. Contacts made at the international meeting with the Director of IHPP and the Coordinator of the Task Force on Health Research for Development enabled the Working Group to proceed with the organisation of a national ENHR workshop in Uganda.

2.2 The Mweya ENHR Workshop

The National ENHR Workshop was held on 18–20 February 1991 at Mweya Safari Lodge, situated in Queen Elizabeth National Park, about 500 km from Kampala[6]. The MOH and the UNCST jointly hosted the workshop, while the IHPP in Washington provided the funding.

Workshop objectives

The overall goal of the Mweya workshop was to initiate and advance the implementation of ENHR activities in Uganda. The specific objectives included:

- to promote and explain the concept of ENHR to senior policy makers and managers in health and other related fields, and to leading researchers in the country
- to provide a forum for the exchange of information on research in Uganda
- to examine and plan specific strategies to encourage the implementation of ENHR in Uganda
- to initiate collaboration and networking within the country and the African region.

Workshop participation

Participants in the workshop consisted of senior officials and scientists drawn from the following categories:

- politicians, including a Deputy Prime Minister
- health policy makers and decision-makers
- policy makers and decision-makers from the Ministries of Health (Permanent Secretary, Director of Medical Services and Assistant Directors of Medical Services), Local Government, Education (Secretariat for School Health Education), Agriculture (Secretariat for Agricultural Research), and Planning and Economic Development
- district health managers (District Medical Officers)
- chairpersons of professional health associations (the Uganda Medical Association and the Uganda Nurses and Midwives Associations)
- staff of the research units in the Faculty of Medicine, Faculty of Social Science and research institutions
- NGOs
- representatives of UNCST.

Representatives from these varied sources were selected in order to involve different disciplines and sectors from the outset. For many participants, this was a rather unusual composition for a workshop on health research, where they expected only medical researchers. It proved to be a unique opportunity for each category of people to discuss health-related research in Uganda.

External participants representing the following organisations or bodies also attended the meeting:

- The Task Force on Health Research for Development (predecessor to COHRED)
- The International Health Policy Programme (IHPP)
- McMaster University College of Sciences, Canada
- University of Hull, Faculty of Sociology and Social Anthropology (UK)
- Suez Canal University, Faculty of Medicine, Egypt
- The National Institute for Medical Research, Tanzania.

The Third Deputy Prime Minister, responsible for the overall monitoring of government policy and programme implementation in the social services sector, officiated at the opening ceremony of the workshop. The Minister of Health was also in attendance. The high-level representation reflected the Uganda Government's political commitment to the concept of ENHR as a vital component of health and economic development.

Workshop findings

The meeting resolved that ENHR be institutionalised within the UNCST, and the following recommendations were made:

- the ENHR concept should be endorsed and adopted by the Government of Uganda
- an Ad hoc Committee should be formed to facilitate follow-up activities

- membership of the Ad hoc Committee would comprise one person from each of the following: the Faculty of Medicine, the Faculty of Social Sciences, a research institute, the MOH, the Ministry of Local Government, a local NGO and the community. The appointing authority would be the UNCST
- the key tasks of the Ad hoc Committee were:
  - promoting ENHR by awareness raising and mobilisation at all levels including communities
  - facilitating the process of setting priorities through consultation with researchers, policy makers and communities
  - collecting information on national health situation analysis and an inventory of health research
  - identifying a suitable organisational structure to coordinate ENHR activities in the country
- the Committee should complete its work in six months and report to UNCST.

To derive maximum benefit, it was decided that health research should include all sectors and disciplines. The workshop also called for greater and more sustained financial support for research on the part of international sources of funding that were to be mobilised to supplement national investment.

2.3 The Ad hoc Committee on ENHR

Because of the bureaucratic system of government, the appointment of the Committee took a long time (nearly eight months). The Task Force in Geneva, Switzerland, implementing the recommendations of the Commission on Health Research for Development, provided funding to support the activities of the Ad hoc Committee, which may be summarised as follows:[7]

Consultation with policy makers and decision-makers

Senior officials of the MOH and other relevant ministries were consulted through personal interviews. The Ministries involved were: Health, Local Government (responsible for PHC at community level), Agriculture, Planning and Economic Development, and Education. Members of the Ad hoc Committee explained the concept of ENHR to the officials. During the discussions, the officials suggested how their contribution could lead to an integrated approach to health research, and how research findings could help them to make informed decisions, which would be the basis for policy formulation and action for health development of the people. Many officials informed the Committee that the success of ENHR would depend on whether or not the researchers oriented themselves towards the new strategy.

Consultation with health researchers

The Medical Committee of the National Health Council, the predecessor of UNCST, had compiled a list of medical research priorities. This list was drawn up by medical specialists, based on the disease burden (**Table 1-1**). The challenge facing the Committee was to ascertain if researchers would accept a new method of defining research priorities. Consultation with researchers about the current status of health research was carried out through a self-administered questionnaire designed by the Ad hoc Committee. Analysis of the questionnaire showed that about two thirds of the research completed and ongoing was biomedical, and only one third was community-oriented. Research planned for the year 1992 was almost equally distributed between biomedical and community-oriented topics. In most cases the research was not multidisciplinary. Furthermore, the Committee found that the research, whether completed, in progress or planned, was not relevant to the priorities set by the Medical Committee of the National Research Council.

The Committee interviewed senior researchers, many of whom had attended the ENHR workshop. The majority of them were in favour of developing a national research agenda, but they feared that the lack of funding would be a major constraint. In addition to these consultations, the Committee reviewed literature to find out what type of health research had been undertaken in the country over the last few years.

Consulting with communities

Four districts, one from each region of the country, were selected for consultation with the communities, but because of insecurity in the northern region, only three districts participated in the discussion of what they perceived to be their health problems. Members of the Ad hoc Committee visited each district and explained the purpose of the consultation to the District Medical Officers and other senior officials. In each district there was a two-day seminar involving the District Planning Committee and the District Health Team. Some members of the Planning Committee were local politicians representing counties in the district. After the seminar there were focus group discussions in one or two villages of the same district. Participants in the village discussions included men and women, young and old.

Members of the Ad hoc Committee were impressed by the keen interest of the people in a frank discussion of their health problems. Unlike the researchers, whose priorities were based on disease burden, communities took a more holistic view of health problems. All communities expressed the view that emphasis should be placed not only on disease, but on fighting the factors that predispose people to ill health. The following is a summary of the health problems perceived by the people in the three districts:

(i) Iganga District (Eastern Uganda)

- *socio-economic factors:* Poor family income, lack of markets for their produce, poor nutrition, poor water supply, poor sanitation, harmful cultural practices, polygamy, unfair land distribution system and increasing population leading to overcrowding
- *administrative problems*: Poor communications system, including bad roads, unsatisfactory distribution of health facilities, lack of capable health care workers, inadequate remuneration of health workers and few schools for children
- *environmental degradation:* Over-drainage of the swamps for growing rice, irregular rains and poor soil due to overuse
- *medical problems:* The following diseases were considered to be common: diarrhoea, malaria, respiratory tract infection, intestinal worms, eye diseases, AIDS, ruptured uterus, tuberculosis, skin diseases.

(ii) Mukono District (Southern Region)

- *socio-economic factors*: Unsafe water supply, non-use of pit latrines, illiteracy, harmful cultural practices, promiscuity leading to AIDS, poor parental care, lack of appreciation of health education, low family income
- *medical problems:* Common Diseases were diarrhoea, malaria, trypanosomiasis, AIDS, skin diseases, intestinal worms.

(iii) Hoima District (Western Region)

- *socio-economic factors:* Poor road transport, lack of general information on health, illiteracy, low family income, harmful traditional beliefs and alcoholism
- *medical problems:* Common causes of morbidity were upper respiratory-tract infection, diarrhoea, and malnutrition, especially in children.

Health Statistics

The Committee obtained the following statistics from the MOH (**Table 2-1**, **Table 2-3, Table 2-3**). The data were obtained from 17 out of 39 districts.

Table 2-1 Common causes of morbidity in 7 million out-patients of all ages from 17 districts for the year 1990

Condition	Per Cent
Malaria	22.6%
Upper respiratory tract infection	15.6%
Trauma	9.1%
Intestinal parasites	7.7%
Diarrhoea	7.0%
Lower respiratory tract infection	5.9%
Skin diseases	5.6%
Eye diseases	4.5%
Ear diseases	2.1%
Anaemia	1.1%
Other diseases	18.8%

Table 2-2 Common causes of mortality in 73,500 admissions to 20 hospitals from 17 districts for the year 1990

Condition	Per Cent
Malaria	14.2%
AIDS/HIV infection	9.6%
Diarrhoeal diseases	8.7%
Pneumonia	7.9%
Anaemia	7.3%
Non-meningococcal meningitis	5.6%
Nutritional deficiencies	5.4%
Tuberculosis	4.5%
Tetanus	3.3%
Trauma	3.1%
Other diseases	30.7%

Table 2-3 Other important statistical data

Condition	Per Cent
Low birth weight (kg)	16%
Underweight (under five years old)	23%
Stunted (under five years old)	45%
Wasted (under five years old)	5%
Immunisation drop-out rates	29%
Accessibility to functioning safe water source	20%
Households with hygienic latrine	15%
Number of persons per doctor (1991)	28,000

Linkages

Formal linkage with relevant ministries and organisations was to be channelled through UNCST. The Committee recommended the need for links with the local authorities as well as with Urban and District Administrative Authorities. External linkages were also to be initiated by UNCST.

Report of the Ad Hoc Committee

The Ad hoc Committee identified the constraints under which efforts to launch ENHR were operating. These included inadequate resources, a limited infrastructure and facilities and an acute shortage of trained manpower. There was only limited support for indigenous and traditional medical research and a lack of involvement and active participation of the communities, the consumer and beneficiaries of research. It recommended that top priority be given to manpower training and development for capacity building, and that a coordinating unit be set up within the UNCST to speed-up the development and implementation of the ENHR Plan of Action.

Chapter Three: The ENHR mechanism

3.1 Initial networks

By 1990 when the ENHR Strategy was first promulgated by the Commission on Health Research for Development, the groundwork for ENHR had already been laid in Uganda. By the time the Commission published its report and International Networks issued the Puebla Declaration to support ENHR, four of these Networks had units firmly based in Uganda, namely the:

- International Network of Community-Oriented Educational Institutions for Health Sciences
- International Network for Capacity Building for Child Survival and Development
- International Clinical Epidemiology Network
- International Health Policy Programme.

The *ENHR Forum*, a newsletter for the exchange of ideas and experiences in promoting Essential National Health Research, summarised in its September 1990 edition the groundwork already laid for ENHR in Uganda[8]. The article outlined the various research units and activities described above and concluded:

> *Potential participants from government, academia and international programmes with local representation have all expressed an interest in launching ENHR activities .... The challenge now is to define priorities for ENHR and to coordinate work from various sectors to bring those priorities into focus.*

The UNCST was established a few months after the publication of the report by the Commission on Health Research for Development. The Council and its committees provided the skeleton, while ENHR activities were to be the flesh and blood of the Council and its Medical Sciences Committee. Thus, one of the initial actions of the Council was to organise the first ENHR Workshop in Uganda, in February 1991.

3.2 ENHR organisational structure

One of the recommendations of the Ad hoc Committee proposed a suitable organisational structure for ENHR to include:

- a cross-sectoral approach — i.e. that ENHR has to be implemented within a cross-sectoral and multidisciplinary organisational delivery system
- the need to devise and put in place a strong, effective and feasible coordinating mechanism for health research activities which were, at that time, scattered among various ministries, institutions and organisations at all levels
- an organisational structure for ENHR that provides for integration of policy makers, implementers and beneficiaries from top level down to grass-roots. The structure should, therefore, allow all groups involved to participate actively and fully in the programme and should also allow the benefits of ENHR to reach them all
- UNCST should set up a functional ENHR coordinating unit embracing all cross-sectoral research activities using the ENHR approach, and ensure an effective mechanism for monitoring them
- the coordinating unit should be under the direct supervision of the Executive Secretary of UNCST, and would be guided and directed on policy and other major issues by the UNCST through the Medical Sciences Committee

- the coordinating unit should be managed by an experienced and comprehensive team of experts, headed by a specialist in research programme formulation and coordination, and assisted by specialists in data collection, analysis, documentation and publications. The unit should be provided with secretarial services, logistics and equipment to enable it to perform its duties effectively
- the coordinating unit should carry out its duties in close collaboration with the MOH in order to ensure consistency between ENHR activities and national health policy and priorities
- the proposed functions of the ENHR coordinating unit were to include:
  - a direct channel of communications between UNCST and other relevant ministries, institutions, organisations and researchers
  - advising UNCST on matters relating to ENHR policies, priorities, strategies and resources
  - coordinating and directing ENHR programmes and resources
  - monitoring the implementation of the ENHR strategy
  - collecting and analysing data and information from research reports and findings
  - publishing regular reports on activities to implement ENHR
  - mobilizing policy makers, implementers and grass-roots communities about the ENHR approach and activities
  - facilitating information dissemination.

In 1997, a national ENHR Consultative Meeting reviewed the ENHR Plan for the period 1993-1996 and discussed the plan proposed for the period 1997-2001. The new Five-year ENHR Plan was approved and launched in 1997, to be reviewed every one or two years. It supports the implementation of the National Investment Plan for the period 1997-2001.

3.3 Advocacy

Since the first Mweya workshop in 1991, there have been systematic efforts to promote ENHR in research institutions, districts, MOH headquarters and the UNCST. The latter set up a small ENHR Multidisciplinary Committee to pursue the promotion of ENHR activities. The ENHR Committee studied the report of the Ad hoc Committee and the Three-year Health Plan drawn up by the UNCST for 1993-1995. On this basis it drafted an ENHR Plan for the same period. Senior researchers and officials of the MOH and the Health Committee of UNCST discussed the draft plan and reached consensus on a final text.

3.4 ENHR Plan

The objectives of the 1993-1996 ENHR Plan were to create a sustainable science culture in which research findings would play a significant role in guiding policy formulation and action to improve the health and development of the people, particularly the least advantaged, by maximising the use of scarce resources. The principal activities included:

- facilitating dialogue among policy makers, researchers and the people
- identifying priority health research problems by involving the same three constituents
- maximizing the use of research findings by involving the three constituents at all stages of the research process, from planning to application of results
- strengthening research capacity in research institutions and at the community level

- monitoring and evaluating progress in implementing ENHR
- developing ENHR networking at the national and international levels.

Research projects formed an important component of the Plan and fell within the broad priority areas for health research, as determined through the Ad hoc Committee mechanism and the MOH Three-Year Plan to strengthen primary health care in the country. Ninety per cent of the budget for the Three-year ENHR Plan was to be spent on research projects and only ten per cent on capital management.

The Second Plan (for the period 1997-2001) is built on the work initiated in 1993-1996. The priorities of the plan are basically the same, with the continuing focus on advocacy, research capacity building, research priorities, networking, management, evaluation and the budget required to implement the plan. As with the previous plan, its general objective is to develop and sustain a science-based culture, in which health research plays a significant role in guiding policy formulation and action to improve health and development of the people of Uganda, particularly the least advantaged, by maximizing the use of scarce resources.

3.5 UNHRO

The sustainability of ENHR in Uganda is a challenge. The Uganda National Health Research Organisation (UNHRO) secretariat has recently been established under the MOH to promote and coordinate health research in the country. The functions of the ENHR Committee under UNCST have been taken over by the new organisation. It has a small secretariat, supported by the Carnegie Corporation in New York, which provides the following technical services for the Committee[9]:

- to create a sustainable science culture in which health research plays a significant role in guiding policy formulation and action to improve the health and development of the people in Uganda;
- to evolve and set up an ethical code for the conduct of health research in Uganda
- to identify, set and guide the formulation of National Health Research Policies and development of a National Health Research Plan
- to facilitate dialogue between the policy makers, researchers of different disciplines, health providers and communities in order to ensure that research is relevant to the needs of the people and that research findings are utilised by the relevant stakeholders
- to facilitate consultation with policy and decision-makers, researchers of different disciplines, and communities in the identification of health research priorities which are consistent with the National Health Research Plan
- to register, renew and co-ordinate different types of health research in the country and promote multidisciplinary and cross-sectoral research collaboration in a bid to establish Essential National Health Research which is consistent with the National Health Research Plan
- to develop, strengthen and supervise Health Research Institutes presently under the MOH and any others established
- to facilitate UNHRO Institutions, other organisations and persons affiliated to UNHRO in the mobilisation of resources for their approved Research Projects and Health Research Plan
- to strengthen the National Health Research Capacity in research institutions, including the MOH and Communities, and develop a quality human resource infrastructure which is capable of responding to the essential research demands of the country.

The management of ENHR is currently under UNHRO. Its secretariat has a Steering Committee consisting of the heads of the following institutions:

- Faculty of Medicine, Mbarara University of Science and Technology
- Faculty of Medicine, Makerere University
- Faculty of Social Sciences, Makerere University
- Institute of Public Health
- Joint Clinical Research Centre
- Makerere Institute of Social Research
- Natural Chemotherapeutics Research Laboratory
- Uganda Cancer Institute
- Uganda National Council for Science and Technology
- Uganda National Health Research Organisation
- Uganda Trypanosomiasis Research Organisation
- Uganda Virus Research Institute.

3.8 National Health Policy and Five-year Health Sector Strategic Plan

In 1999, a National Health Policy and Five-year Health Sector Strategic Plan was developed in Uganda. The overall objective of the policy is to reduce mortality, morbidity and fertility, and their disparities. ENHR is mentioned as one of the strategies to reach this goal, and as one of the important support services that are necessary for the successful delivery and implementation of the minimum health package[10].

Within this policy, the Government has reorganised and restructured institutions affiliated to the MOH in order to enhance their performance. UNHRO is amongst those institutions and in the Strategic Plan it is clearly stated that health and health related research would be organised and coordinated by UNHRO[11]. The primary objectives of UNHRO as defined in the Strategic Plan are as follows:

- to undertake research on the trends and economic consequences of disease, disability and ill health
- to develop capacity for research at all levels
- to provide guidance for the implementation of the Health Policy and Strategic Plan.

At the national level, the UNHRO secretariat will provide overall coordination and guidance for research and development throughout the country as well as technical back-up and support to districts. The secretariat will be responsible for mobilising resources; setting a priority research agenda; mobilizing the relevant skills and resources to analyse, disseminate and utilise health research results; commissioning and organizing health research in collaboration with other research and academic institutions, NGOs and other related national and international organisations.

At the district level, the District Director of Health Services will be responsible for identification of research priorities and the coordination and organisation of research.

Professor Raphael Owor, the national ENHR Focal Point and former regional ENHR Focal Point, is appointed Director of UNHRO. He is guided by a Steering Committee composed of heads of health research institutions to assist in the management of UNHRO secretariat and enhance the establishment of efficient health research systems.

Chapter Four: Priority setting

4.1 Setting research priorities

The Ad hoc Committee recommended broad areas of research priorities based on the criteria of avoidance of duplication, feasibility, political acceptability, capability, urgency and ethical acceptability. The priority research topics included:

- maternal and child welfare and nutrition
- water and sanitation
- communicable diseases, including HIV/AIDS
- health and health policy analysis.

4.2 Review of priority setting

A review of priorities took place in the context of the Second National ENHR Plan (1997-2001). This included consultations with research scientists, policy and decision-makers, and District Health Management Teams; a review of health statistics; a review of relevant literature and a National Consultative Conference. The following broad priority research areas were adopted:

- maternal, child health and nutrition
- water, sanitation and environment
- communicable diseases
- non-communicable diseases
- health policy and health systems
- drug use studies.

Within these broad priority areas, each research institution is encouraged to set its own research priorities and projects. Currently, most health research in Uganda relates to the recently revised national health research priority areas. These also form the basis for the country's 1997-2001 Five- year Plan and the ENHR Plan. The full list of priority areas is set out below.

Maternal, child health and nutrition

- infant mortality and morbidity trends
- maternal mortality and morbidity trends
- socio-economic and cultural factors in maternal and child health and nutrition
- monitoring systems for the health of pregnant mothers
- community perception and concern about health
- patterns of health seeking behaviour
- reproductive and sexual health of adolescents
- adolescent health needs and interventions for promoting adolescent health
- improving access and quality of care for Maternal and Child Health/Family Planning Services
- assessment of the EPI programmes

- studies on street children and orphans
- development and assessment of appropriate information, education and communication (IEC) messages for MCH
- the role of the household in promoting childcare
- epidemiology of nutritional disorders, intervention and prevention strategies to the essential research demands of the country.

Water, sanitation and environment

- waste management
- water supply and use in the community
- environmental health problems
- water purification methods at the household level
- impact of industrialisation on environmental health
- occupational health.

Communicable diseases

(i) *STI and HIV/AIDS*

- the burden of HIV/AIDS care (community and institutional)
- effective management of HIV/AIDS associated and opportunistic infections
- examination of AIDS control/awareness initiatives/ strategies/programmes
- improving the quality of life of PLWHIV/AIDS
- gender and AIDS
- STI in adolescents
- social and behavioural factors that could be used to develop culturally appropriate control interventions
- research on drugs for management of HIV/AIDS, including traditional regimes
- basic research on HIV.

(ii) *Tuberculosis*

- cost-effective treatment programmes
- compliance with TB treatment
- epidemiology and management of drug resistant TB
- feasibility of community-based care
- TB care among special groups.

(iii) *Control of tropical diseases* e.g. malaria, trypanosomiasis and schistosomiasis.

(iv) *Management and control of diseases of epidemic potential* (e.g. plague, meningococcal meningitis and cholera.

(v) *Epidemiology and effective management of diarrhoeal diseases.*

(vi) *Socio-economic aspects of communicable diseases* (e.g. Cost-effectiveness studies).

Non-communicable diseases

- control and management of endocrine/metabolic diseases (e.g. diabetes mellitus, hypertension)
- epidemiology and management of common mental disorders
- trauma and injuries
- management and control of sickle-cell disease
- epidemiology and management of common cancers
- management of common disabilities.

Health policy and systems

(i) *Health Policy*

- cross-sectoral collaboration and coordination mechanism in health care
- development of health policy, review and analysis
- health sector reforms
- alternatives for health care financing
- donor impact on health
- comparative studies on the burden of disease
- the role and extent of the private sector component of health service delivery.

(ii) *Health Systems*

- community Health Information System
- improving access to, and quality of, care
- effective use of health resources
- development of interventions to improve referral system
- evaluating training programmes for health workers.

Drug use studies

- irrational drug use and prescription problems
- drug use in the community and self-medication
- studies on drug distribution mechanisms
- drug resistance studies
- drug regulatory mechanisms
- studies on traditional/herbal medicine and practices
- alcohol and other substances of abuse.

Chapter Five: Capacity building

5.1 Work of the Ad Hoc Committee on ENHR

In its deliberations on research capacity, the Ad hoc Committee on ENHR (1994) i n Uganda noted that research output was very low. It was noted that health research in Uganda was concentrated in the areas of clinical and laboratory sciences, and was largely descriptive[7]. Because of the orientation of individual researchers and research institutions, few studies had been directed towards health policy and action. The Ad hoc Committee further observed that science and technology in the country are underdeveloped and poorly funded. Moreover, the links between research and improvements in health are not fully appreciated by researchers and health professionals. In addition, there are few incentives for applied multidisciplinary research, and little attention is paid to the need to present research results in ways that are comprehensible to the users.

5.2 Limitations and deficiencies

The Committee identified specific limitations to the research capacity in the country due to inadequate research training; intellectual isolation; low salaries and few possibilities for promotion; the absence of or limited career paths; and restricted choice of research topics. Institutional deficiencies included inadequate staff and facilities, a poor understanding of the relevance of research to the solution of health problems, lack of access to information, and institutional instability.

At the national level there was a lack of demand for research and scientific information, as well as a lack of understanding of the relevance of research to the solution of health problems. In general there was a poor public grasp of the value of research and little support, including a lack of political commitment and an absence of an agreed plan for health research. Research policy was subject to changes due to political instability and bureaucratic rigidity. There was difficulty financing health research on account of inadequate funds and poor support from external funding agencies for research capacity building to meet national needs and priorities.

In addition to the problems of isolation, capacity building was badly needed in areas such as breadth of scientific expertise, institutional infrastructure and information systems.

5.3 Developing national health research capacity

Since the inception of the ENHR process in Uganda, efforts have been made to address the above deficiencies in a number of ways. Workshops to discuss the merits of individual research proposals have been organised. Certain research proposals have been put forward in consultation with the MOH. International research networks have been involved in promoting national research capacity, and there has been follow-up action with donors to support national research initiatives. In 1995, a national ENHR workshop reviewed research papers, identified possible sources of funding and discussed the strengthening of research capacity. Through national and international partnerships a Master's Degree Course in Clinical Epidemiology and Biostatistics was recently introduced in Makerere Medical School. The course is multidisciplinary and based on the ENHR philosophy.

5.4 May 1998 workshop on capacity development for ENHR

In 1998, Uganda participated in a study on Capacity Development for ENHR, which included the assessment of research capacity in the country and a workshop to discuss the findings. An interdisciplinary study team was assembled under the leadership of Professor Raphael Owor.

Objectives

The team set itself three objectives:

- to review Uganda's current capacity to conduct, use and manage priority driven health research
- to use the results of the review to develop a Capacity Development Plan as an integral component of Uganda's new ENHR Plan
- to contribute to an international exploration of capacity development for ENHR.

Methods

The study team decided to focus on two categories of institutions and organisations: those directly involved in conducting health research and those which were primarily donors and users of research. An interview protocol was developed which featured relevant aspects of the ENHR process, and the capacity required for implementing ENHR. Team members interviewed key informants from relevant organisations, obtained documents and, where appropriate, conducted an on-site inspection of the existing research infrastructure. A Medline search was conducted for the period 1993-1998 for publications on health research in Uganda. The search yielded 311 articles that were then categorised according to the six health research priority areas, based on the 1997 revision of priorities. Similarly a review of health research projects registered in the database of the UNCST was conducted for the 5-year period 1993-1998. These dates coincided with the time when Uganda's first ENHR Plan was launched, including the initial determination of health research priority areas. In addition, an analysis of health research funding for the same 5-year period was conducted, to determine the amount, pattern and source (national or external) of funding for health research in Uganda.

Study findings

The study found that all but 30 (of 311) publications could be categorised within the six priority areas. The largest cluster of 182 publications was in the category of Communicable diseases, including 107 on the problem of AIDS. Only two publications appeared under another priority area, namely Water, sanitation and environment. Also of interest in this study was the fact that Ugandan scientists appeared as first authors in 123 (39%) of the publications of the period.

The analysis of the UNCST project list showed a similar pattern. Each of the 111 projects could be categorised under one of the six priority areas. Again the largest number (67) appeared under the category of Communicable diseases, most of these related to research on AIDS. Only one project was concerned with Water, sanitation and environment.

Health research in Uganda has been undertaken mainly by researchers at the Makerere University and in research institutes, particularly the Uganda Virus Research Institute and Uganda Trypanosomiasis Research Organisation (UTRO). An analysis of 35 health research projects registered by UNCST by June 1995 shows that 66% were community-based, 23% clinical and 11% basic research. Further analysis of these projects indicates that many of the community-based ones were not multidisciplinary and communities were not involved in the various stages of the research process. This is an area that needs to be improved. In an earlier comparison in 1992, the Ad hoc Committee on ENHR found that 32% of the research projects were community-based, 54% clinical and 14% basic research. There has been an increase, therefore, in the proportion of community-based research. Ugandan researchers are developing most of the current research projects (63%).

Regarding funding for the 5-year period 1993 - 1997, the total budget for the 111 projects was US $11,683,660. Of this amount, only $104,823 (0.9%) came from internal national sources, supporting 19 projects. There was no particular trend over time, other than the fact that in 1997 the sum of all externally funded project budgets was almost $6 million. The results of the survey were discussed in a National Capacity Development Workshop, with representatives of the relevant research organisations, donors and user agencies, government, non-governmental organisations, students and the community.

A plan of action was developed and is currently in the process of implementation.

5.5 Capacity development for ENHR at the district Level

In 1997, the National ENHR Mechanism carried out a series of awareness raising workshops for district health teams on the value of research, which discussed the ENHR Strategy. Following these workshops, health personnel from six districts had two weeks training in Health Systems Research (HSR) methodology and are currently carrying out research.

Uganda has recently adopted various forms of health sector reforms, including decentralisation. Under the decentralised health care programmes, districts become a powerful administrative unit and a lot of decision making is meant to take place at that level. However, while the policy has received strong political support, the districts still lack the capacity to operate effectively.

Given the phenomenon of decentralisation and the problems the districts are facing at the moment, the National ENHR Mechanism has embarked on an exercise to develop the capacity for health research at the district level, as a tool for development. This effort was initiated in January 1999 in the two rural districts of Kamuli and Lira. The process included a visit to the districts by two members of the ENHR Unit. They began with a two-day discussion with various district authorities to introduce the concept of essential health research and its value as a tool for district development. Subsequently, a larger meeting involving various stakeholders in the district was arranged to discuss district health problems, and to set research priorities. Researchers from both districts were invited for a research methodology workshop in Kampala, from 21 to 31 March 1999. Several facilitators guided the two groups through the whole process from implementing research up to the dissemination of results. Currently the researchers have completed their research and are disseminating their findings.

5.6 Masters Programme in Public Health

The MOH, together with the Institute of Public Health, Makerere University, is running a Masters Programme in Public Health. Students are assigned to districts as their field sites, where they spend approximately 75% of their training. Many studies have been carried out by the students and most of the results have been put into action or used in the districts where the research is designed, developed and carried out. Examples of these studies include:

- **Surveillance of measles in Mbarara District:** The findings of this study have led to:
  - the establishment of more outreach activities in the district
  - presentation of a completed immunisation card for the enrolment of children into primary school
  - the repair and replacement of refrigerators located in health centres.
- **Tuberculosis case finding, a laboratory diagnosis in Tororo District:** Following the results of this study, several health units in the districts with qualified medical personnel have been facilitated to perform ZN tests and to carry out examinations. Health education programmes for the community have been started as well.

Chapter Six: Networking

6.1 Internal networking

Effective networking must start at the departmental or institutional level. Researchers in an institution should be aware of what is going on within the institution. Out of this institutional network develops internal national networking.

In Uganda, the implementation of the ENHR strategy depends largely on the institutional networking mechanisms. Currently some 45 institutions are implementing the ENHR strategy locally. The linkage between these institutions is primarily through the sharing of research capacity or research activities. As described earlier in the background to this monograph, some of the research institutions are multidisciplinary. This enables alliances to be formed when carrying out research activities. For instance, the former Health Policy Analysis Group drew researchers from the Faculty of Social Sciences, the Makerere Institute of Social Research, the Child Health and Development Centre, the Institute of Public Health and the Clinical Epidemiology Unit. The Child Health and Development Centre has researchers from the Faculty of Medicine, Faculty of Social Sciences, faculty of Agriculture etc. The ENHR management benefits greatly from alliance with these research units and institutions.

The ENHR process in Uganda recognises the contributions of these research units and institutions. They have participated at different stages of development of the ENHR plan and they are the ones implementing it.

6.2 Regional Networking

ENHR is primarily national, but regional and global networking is necessary and can support the national effort. There is currently strong African regional ENHR networking, and Uganda was the Focal Point up to end of 1999. The Network has held meetings in Mombasa (Kenya), Sogakope (Ghana), Kampala (Uganda), Arusha (Tanzania) and Harare (Zimbabwe), where regional issues were discussed. The issues included:

- sharing experiences on implementing ENHR with the countries in the region
- research capacity building through training visits, consultancies and sharing the use of some facilities
- developing a common research protocol between two or more countries; it should be noted that some donors support research only on a regional basis
- regional meetings to share experiences
- monitoring and evaluation of ENHR at regional level is essential for healthy development of the ENHR concept.

6.3 Global Networking

Uganda is a member of COHRED and is currently represented on the Board. The Coordinator of ENHR in Uganda, Professor Raphael Owor, is the Vice-Chairman of the Board.

Chapter Seven: Financing

7.1 Research funding

It is difficult to estimate how much money has been spent on research in Uganda. The UNCST records for the period January 1993 to December 1994 show a total of US$ 2,090,418 spent on health research in the country. Of this amount only US $14,700 (0.7%) came from the Uganda Government, mainly through Makerere University. The remaining 99.3% was from external sources. The sum of US$ 1,529,418 (73%) was spent on AIDS research and the remaining 27% (US$ 561,000) on other research. No attempt was made to estimate the cost of research capacity building.

In February 1994, the Minister of Health invited external donors to discuss with Ugandan researchers and senior government officials ways of mobilizing resources to support ENHR activities. Since that meeting, discussions have continued with donor agencies to increase research funding, and similar discussions with the MOH are continuing.

Government and external partners will collectively support the Health Policy and Sector Strategic Plan, to be launched in July 2000. Health research is part of the strategic plan and will, therefore, receive funds for some of the research projects. The Government also provides a substantial base for research in terms of premises, human resources, management and administration.

7.2 Health care financing dissemination seminar, 7 March 1995.

The seminar was organised by the Child Health and Development Centre, in collaboration with the Ministry of Finance and Economic Planning and the MOH. Participants included senior government officials, senior researchers from research institutions, local NGOs, donors and health care workers in the districts.

Research findings were presented and discussed under the following headings:

- Household spending patterns for health and investments in vulnerable groups
- Cost recovery at the health facility level
- Community participation and financing initiatives.

At the end of the seminar, participants agreed on the concept of cost recovery and community participation, but they emphasised the need for more efficient use of existing resources.

Chapter Eight: Essential health research at the district level

8.1 ENHR in district development

In 1997, COHRED commissioned a small working group to document and analyse experiences in sub-national/district level health research. The working group, consisting of six country participants and the Regional Focal Point for ENHR, held a two-day brainstorming workshop in Uganda in March 1998. The main objectives were to share experiences in district-based health research, identify the major obstacles, and to propose strategies to address them. The major lessons learnt from the district workshop along with strategies identified to address the problems are summarised in the box below:

Emerging issues

The working group found that there was a limited awareness of the values of research at all levels, matched by a limited capacity for research with a rapid turnover of staff. Resources allocated to research were inadequate. It stressed the need for better research leadership and management, especially in bringing health service providers and the community together as equal partners in research. It recommended that the role of established research institutions be clarified in ENHR development at the district level in the context of a decentralised research support mechanism.

Strategies for dealing with emerging issues

The working group recommended a series of measures to respond to the difficulties it had encountered, as follows:

- **Awareness raising:** National consultative meeting to address ENHR at the district level; followed by district awareness meetings
- **Capacity building:**
  - research training programme for the district
  - in-service training on research methods
  - improving research skills
  - creating partnerships
  - improving leadership and management skills
  - Health Systems Research training
  - review of curriculum in training institutions
  - attachment of researchers to the district
  - study community dynamics and suggest entry points for district research
  - draw up a list of available resource materials for district level research.
- **Resources for Research:**
  - sensitise donors to inject funds for research directly to the districts
  - encourage districts to access donor funds, as well as using existing district funds for research
  - district System Development to promote decision making at the district level.

- **Rapid turnover of personnel:**
  - Short term:
    - target mid-career personnel who are already settled in the district as partners
    - more focus on non-physician health workers.
  - Medium term:
    - contract system could be tried
    - more carefully designed incentives for district attachment system.
  - Long term:
    - districts should have the power to retain their staff as required.
- **Decentralised Research support mechanism:**
  - ethical clearance at district level
  - peer review process at district level
  - prioritising mechanism and drawing district research plan.
- **Role of existing institutions in ENHR development and existing human resources:**
  - universities should reward those engaged in district research activities
  - fostering dialogue with institutions to review change of curriculum to include community based research
  - feedback of research results to the districts.
- **Coordination of various institutional research activities** to address the health problems of the districts.

Chapter Nine: Community participation

9.1 Study on community participation

In 1998 - 1999 the COHRED Working Group on Community Participation conducted five case studies, one of which was in Uganda. The Uganda case study, investigated the following projects:

- Community participation in the control of tsetse flies research in Bugiri district, Eastern Uganda
- Mpererwe community project on the needs assessment survey of persons with AIDS, care givers and orphans in a peri-urban area in Kampala District
- The Pallisa Community Development Trust.

Key issues focused on defining and describing community, community participation, assessment and contextualisation.

Study conclusions

The study concluded that definitions and meanings of community, as well as community participation, depend on who is doing the defining and who is being targeted. It also indicated that criteria for selection of community participants depended on one's level of education, competence and willingness to participate. It drew attention to the advantages of working through existing groups, since they were community-based, and were already mobilised and organised. Similarly it supported the use of existing political and administrative structures as channels of participation. It accepted that limited forms of participation were sometimes inevitable.

Constraints on community participation

A number of factors were consider deterrents to local community participation in health research. They included:

- community fatigue, especially in areas which have been over researched
- too much voluntarism discourages some participants
- lack of benefit from their participation in previous research generates a feeling it is a waste of time
- political interference
- the community wants immediate benefits, most of which take time to mature
- lack of resources to include as many community participants as possible
- gender was not considered in any of the projects. Women were left out despite the fact that they are the primary health care providers at family and household levels
- short duration of a study is not conducive to effective community participation
- dissemination of results was a problem.

Success in enhancing community participation

At the same time a number of factors served to encourage local community participation as follows:

- combining people's daily activities with research and some component of income generating activity, wherever possible, increased participation
- use of existing political and administrative structures is important, as it gave the community members the go-ahead to participate, if the leaders represent the community
- community benefits through learning skills and being sensitised
- involvement of other stakeholders (networking) avoided duplication
- political goodwill is crucial. People will participate once they see their leaders in the forefront.

One major lesson in the Uganda case study is that communities want a say in matters that affect them. It is only when the community is fully participating in a research project by coming up themselves with answers to their identified problem, that the intervention made will be their own. That is when they will feel ownership, will own the outcome, and defend it.

Recommendations

- the duration of the study should provide enough time for the community to participate
- discussions with the community should start from the outset in the questions to be asked and subsequent phases
- the results of the study should be disseminated to the community in the shortest time possible and in a manner they understand
- research proposals should have a component on how the community will be involved to participate
- some facilitation, where needed, is important to avoid disinterest caused by too much voluntarism;
- communities need to be more sensitised to the value of ENHR
- gender concerns should be incorporated in the research process to allow participation of the disadvantaged sex.

Workshop on the report on community participation in ENHR

A national workshop was organised to disseminate the results of the case study. The workshop was attended by researchers and community participants from the areas studied[12].

Chapter Ten: Research into policy and action

10.1 Translation into policy and action

A number of health research findings as follows have been translated into policy and action:

- Findings by the AIDS Commission led to the change in the legal minimum marriage age in Uganda from 16 to 18 years as a way of extending protection of youth from AIDS
- Findings by the Human Trypanosomiasis Research Centre led to the development of monoscreen traps for tsetse flies, which can be made and used by the community
- Research by the Clinical Epidemiological Unit (CEU) on anti-microbial prescription patterns have contributed to the change in the choice of anti-microbials in surgery.

There has been a major effort in Uganda to disseminate research results, especially in the management of AIDS patients and the better use of resources in health care facilities. Unfortunately, the relevance of research to the solution of health problems is still not properly understood, resulting in a lack of demand for research and scientific information.

10.2 Dissemination of research findings

Dissemination of research findings to policy makers, health care providers, communities and researchers is of paramount importance. Research findings should be closely linked to policy formulation and action. The following dissemination activities were organised:

ENHR Workshop for policy development in Uganda 11–12 October 1993.

Participants in the workshop consisted of senior MOH officials, including the Minister, representatives of community-based NGOs involved in health care and senior researchers in different disciplines. The workshop discussed research papers on the use of primary health care facilities; nutrition and food security; use of oral rehydration therapy in the management of AIDS patients and community involvement in the care of AIDS patients. The workshop recommended that:

- more resources be made available to improve Primary Health Care Services at the community level
- activities of NGOs implementing PHC be coordinated
- the Government establish and implement the National Food and Nutrition Policy and Strategy
- greater use of oral rehydration therapy be made and less intravenous fluids in the management of AIDS patients, with greater community involvement in caring for them
- the facilitating and coordinating secretariat work closely with the MOH and the National Council for Science and Technology in the implementation of ENHR.

The Government is acting upon all the recommendations.

Seminar with community leaders in Mukono District on malaria research, 14 February 1994.

Seeta Nazigo community in Mukono District had participated in malaria control research, and on 14 February 1994 the researchers organised a seminar to explain the research findings to the community representatives and local political leaders. At the end of the seminar, the community leaders made the following observations:

- they believed they now understood malaria better
- they had reduced breeding places for mosquitoes in the community
- children suspected of having malaria are taken for early treatment at the health centre
- the research had developed togetherness in handling community health problems
- more women should be trained to participate in the activities of future research projects
- the community would be pleased to participate in the next phase of the research.

Researchers and policy makers also discussed this research on Uganda Television.

Seminar on a baseline survey in Kawempe Community, 14 February 1994

In 1993, teachers and students of the Faculty of Medicine and community representatives in Kawempe community conducted a baseline survey. On 14 February 1994, the faculty and students explained the results of the survey at a seminar organised in the community. The survey's findings indicated that high morbidity could be attributed largely to poor water supply and inadequate sanitation. The community was prepared to work with researchers and local policy makers to carry out research aimed at finding ways to improve the situation.

Workshop on the comparative study of costs, the use of resources and financing of health care services between governmental and non-governmental facilities in Uganda, 16–18 February, 1994.

The workshop was organised by the Health Policy Analysis and Development Group in Uganda. The participants were senior policy makers from the MOH, District Medical Officers, NGOs working in the area of health care delivery, health care providers and researchers.

After the workshop, the Health Policy Analysis and Development Group visited districts that had participated in the study and explained the findings to the district health teams. The research findings emphasised the need to improve services in government facilities in rural areas. This requires more resources, better remuneration of health workers, better maintenance and regular supervision of staff. The Government is taking steps to address these problems.

Health Research Forum 2000

The Forum was attended by researchers, policy makers, including parliamentarians and community representatives from the districts. The papers discussed covered policies in health services and financing.

Chapter Eleven: Conclusions

The ENHR process in Uganda has both achieved successes and been required to take up certain challenges, which are summarised below. The support Government is giving to the UNHRO secretariat and the Steering Committee, as well as the inclusion of health research and development in the Health Sector Strategic Plan are clear signs of governmental commitment to strengthen health research efforts.

11.1 Successes

ENHR mechanism

Right from the introduction of ENHR in Uganda, the UNCST embraced the ENHR concept, and in collaboration with the MOH has spearheaded its implementation. Under the leadership of UNCST, research priorities were identified and the first national ENHR Plan was developed. Both the Plan and priorities were reviewed in 1997. The ENHR Committee, under the UNCST, has stimulated dialogue with senior officials of the MOH and other relevant ministries. One very important consequence of this dialogue is that the MOH is now demanding evidence-based decisions. The ENHR Committee and its successor, the UNHRO Steering Committee, have organised several workshops to disseminate research findings, and MOH senior officials have shown increasing interest in these workshops, suggesting there will be greater demand for the use of research findings. Through the ENHR arrangements we have been able to raise external funds to support the application of the ENHR strategy. The UNHRO secretariat receives financial support from the MOH. It is expected that when the Health Sector Strategic Plan becomes operational in July 2000 more funds will be made available to support certain research projects.

Promotion and advocacy

Since the first national multidisciplinary and cross-sectoral ENHR workshop in February 1991, there have been systematic efforts to promote ENHR in research institutions, districts, MOH headquarters and the Uganda National Council for Science and Technology. This was made possible by the ENHR Committee, which was administratively supported by the Council. The UNHRO Steering Committee and its secretariat have continued to promote ENHR in the research institutions and among policy and decision-makers. It can be stated that most people in those institutions and organisations are now fully aware of ENHR.

Networking

Internally, the networking of research institutions and international research networks operating within the country has been successful. The UNHRO secretariat is developing a resource centre to facilitate the networking process. Regionally, Uganda is a Focal Point for the ENHR Africa Network.

11.2 Challenges

Research capacity

The process of implementing ENHR in Uganda has suffered certain drawbacks, especially in the area of research capacity. There are few researchers, and many are young and inexperienced. Furthermore, research funding is grossly inadequate. There is, however, great interest in the ENHR initiative in the country. The Government has shown strong political will and researchers are cooperating wholeheartedly to ensure success.

Community participation

Community involvement is still limited, but is expected to improve when districts become more involved in the research process.

Funding

Internal financing of research is very poor and most funding is international. We have yet to convince government bodies and local NGOs to increase their investment in health research.

Capacity building

Research capacity building has not been adequately addressed and there is a need to review the national plan for capacity building.

Evaluation

There has been no internal evaluation of the ENHR process, and there is also a need to develop a workable evaluation instrument.

Sustainability

The sustainability of ENHR in Uganda is a challenge, but a statutory mechanism based on the ENHR strategy and known as the "Uganda National Health Research Organisation" is in the process of being established to promote and coordinate health research in the country. The activities of this body will be financed mainly by the Government, and functionally it will collaborate closely with the MOH. The functions of the UNHRO Steering Committee will be taken over by the new statutory body.

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