Proceedings of the First Essential National Health Research Congress on Priority Setting

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COMPILED BY:

DIRECTORATE RESEARCH COORDINATION AND MANAGEMENT
DEPARTMENT OF NATIONAL HEALTH
P/BAG X828
PRETORIA, 0001
SOUTH AFRICA

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Dr L.E. Makubalo(DOH)
Dr Debbie Bradshaw(MRC)
Ms Annemieke von Middlekoop(CSS)

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Ms Jane Edwards(HST)
Ms Gcinile Buthulezi(HST)
Ms Nonhlanhla Makhanya (HST)
Ms Natasha Palmer(HST)
Dr Linda Richter(MRC)
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CONTENTS

ACKNOWLEDGEMENTS **2**

CONTENTS **3**

EXECUTIVE SUMMARY **4**

1. FOREWORD **6**

2. THE ENHR PROCESS IN SOUTH AFRICA **7**

3. PRIORITY SETTING **9**

3.1. The aims of the congress 9

3.2. Criteria for prioritisation 9

3.3. Congress participants 11

4. CONGRESS PROCEEDINGS **11**

4.1. STEP 1: Ranking of priority health problems/disease 11

4.2. STEP 2: Identification of broad research areas 16

4.3. STEP 3: Discipline specific priorities 22

5. CONCLUSIONS **26**

6. THE WAY FORWARD **26**

7. CONGRESS EVALUATION **27**

ANNEX 1 ..... **28**

ANNEX 2 ..... **30**

ANNEX 3 ..... **32**

EXECUTIVE SUMMARY

1. AIMS OF THE CONGRESS

The First Essential National Health Research Congress was held between 14-15 November 1996 in Pretoria with the aim of:

1.1. Identifying health research areas that address priority health problems

1.2. Developing a process for consensus building

1.3. Facilitating the establishment of and ENHR Committee

1.1. IDENTIFICATION OF PRIORITY HEALTH PROBLEMS

1.1.1. Congress process and criteria

The Congress process was designed as a stepwise process using criteria as recommended by the ENHR Task Team Report[1] of 1995.

1. Ranking of health status, based on **burden of disease** and **perceptions of participants**

2. Identification of broad strategic research areas for the top 10 health problems based on **the current interventions available**, **success of current interventions,** and identification of the research discipline of the intervention.

1.1.2. Priority health problems identified

The Congress participants identified 45 health areas that constituted priority health problems of the country. The top ten health problems identified included: Injury/Violence, TB, Nutrition, HIV/AIDS, STD's, Cancers, Diarrhoea, Respiratory Infections, Mental Health (excl. substance abuse) and Malaria.

However, Congress participants felt that this priority list should be further refined.

1.1.3. Strategic research areas and opportunities identified

Several research areas and research questions were identified by Congress participants for each of the top ten diseases. The spectrum of research represented the essence of ENHR. Each of the national priority health problems were addresses by a range of methodologies, and as expected the range of research methodologies was different for each health problem.

Congress participants, however felt that these research questions should be further

refined by experts.

1.1.4. Discipline specific concerns

In addition to identifying the health research priorities as outlined above, the participants (at the request of the meeting) were also divided into discipline specific groups. The purpose of these groups was to address the discipline specific priorities within the context of the top ten health problems. However, these discussions only reiterated the other elements of the ENHR strategy, viz., Capacity development, funding mechanisms, evaluation and monitoring and networking, instead of identifying specific priorities which were related to the top ten health problems that were identified.

1.2. DEVELOPING A PROCESS FOR CONSENSUS BUILDING

The generation of a priority health problems list as well as a list of strategic research areas and questions attests to the success of the prioritisation Congress as a consensus building exercise. Of particular note should be the discussions held with participants during the Congress which allowed them to determine and express their priorities and concerns with regards to the Congress process.

1.3. ESTABLISHMENT OF AN ENHR COMMITTEE

The Congress was used as a launch to obtain nominations from participants for the national ENHR Committee. This process , based on the recommendations of participants, will be further refined by inviting nominations from a larger group of stakeholders and nominees will be appointed by the Minister.

1. FOREWORD

Essential National Health Research (ENHR) as a strategy was initially proposed by the Commission on Health Research for Development (COHRED) which was housed within the World Health Organisation (WHO). The ENHR concept was developed in order to harness the enormous, but generally neglected, power of research in improving the health of people.

1.1. Equity and ENHR

The Commission's report(*Health Research: Essential link to Equity in Development)*[(1)] emphasises the need for equity in health research. Equity refers to the provision of a service which is based on people's needs rather than their social and economic status. To achieve equity requires changes in the way in which research areas are identified, resources such as funding and personnel are allocated, and in the manner in which research results are disseminated and received by the users.

Research as a tool, therefore, needs to focus on gains based on sustainable efficiency and effectiveness impacts of research. It is within this context that the ENHR strategy was developed by COHRED.

1.2. The aims of the ENHR

ENHR is an integrated strategy developed to facilitate advancement towards attaining the goal of equity in health research, and to operationalise this concept by advocating an inclusive process for priority setting and research management.

The task of ENHR is to manage health research (funding, priority setting and capacity building) on a national basis and to use that research effectively, in order to promote health rationally and equitably. The emphasis of ENHR activities is on the inclusion of intersectoral and multi-disciplinary stakeholders: researchers, policy makers, health care providers and the community, to ensure the successful implementation of the strategy.

1.3. The focus of ENHR

The content of ENHR includes the traditional types of research commonly referred to as epidemiology, social and behavioural research, clinical and biomedical research, health systems research and policy analysis; **BUT** it is specifically oriented towards the most important problems affecting the population, with particular emphasis on the poor, disadvantaged and other vulnerable groups whose health needs are often overlooked or ignored.

ENHR also addresses health issues that occur at a global, regional, national and local levels. At the national and local levels, it is important to examine health and disease patterns, determinants and risk factors for disease that address country specific needs, and the operations of existing health services. Biomedical or clinical research

may have a regional or global implication, where science can also contribute to the total world knowledge pool. Prioritising research areas therefore needs to nurture the science capacity itself, while addressing vital national needs.

Implementation of an ENHR strategy can result in resources being used more effectively and efficiently. At any level of spending, good information, based on sound research and adapted to stakeholders needs, will contribute to greater efficiency in the allocation of resources and provide a more effective mechanism of reducing the inequities in health.

2. THE ENHR PROCESS IN SOUTH AFRICA

Background to the ENHR process in South Africa

Discussions on the process of the adoption of ENHR in South Africa began between interested parties in 1991 and in 1993, five representatives of organisations involved in community based research in South Africa, attended the Geneva conference on ENHR. The representatives at this conference were from the Health Systems Development Unit (HSDU, an NGO), the Medical Research Council (MRC, a statutory council), the Health Systems Trust (HST, an NGO) and SAHSSO (a professional based NGO) and the National Progressive Primary Health Care Network (NPPHCN, also an NGO).

In April 1994, in support of the ANC policy[(2)], the MRC and the alliance of progressive health NGO=s also endorsed ENHR. In December 1994, the new Department of Health took the initiative by organising a national meeting of stakeholders in health research, to plan the implementation of ENHR. This national workshop served to raise the awareness of ENHR among the participants and highlighted the concern of many role-players regarding the future of health research in South Africa. Most workshop participants were willing to consider the role of ENHR in South Africa, and its relevance to their particular constituency.

In March 1995, the Minister of Health appointed a National Technical Committee to further develop recommendations for the implementation of Essential National Health Research.

The mandate of this committee was as follows:

* To identify issues and questions raised at the December 1994 meeting for further deliberation or investigation.

* Investigate appropriate answers to questions raised at the December 1994 ENHR meeting.

* Develop options for the way ENHR could be co-ordinated, funded and implemented in South Africa.

* Identify the total budget for health research in South Africa from statutory sources and determine how these resources could be maximised to support health service management.

The ENHR task team report[3], with its recommendations, was presented to the Minister in November 1995 and was further discussed at a workshop during February 1996. The task team report and February workshop recommendations included all of the seven elements of ENHR.

Both the task team and workshop participants agreed that the national priority setting process needs to include the participation of civil society with a special focus on co-ordinating the multi-disciplinary, intersectoral priority setting process, at the district and provincial levels.

It was also recommended that the priority setting process should be:

- goal/solution oriented
- based on the analysis of health status, burden of disease and developmental needs.

Workshop participants recommended that priority setting should be co-ordinated by a national body with task teams around specific health and developmental issues.

The National Department of Health took the process of the implementation of the ENHR strategy one step further, by identifying ninety five major stakeholders in health research in South Africa.(Table 1)

TABLE 1 : LIST AND NUMBER OF ORGANISATIONS AND INSTITUTIONS IDENTIFIED AS STAKEHOLDERS IN THE ENHR PROCESS

Organisations	Number
UNIVERSITIES	12
NGO'S	10
SCIENCE COUNCILS	7
PROFESSIONAL ASSOCIATIONS	7
TECHNIKONS	6
NURSING COLLEGES (EXCLUDING UNIVERSITIES)	21
PRIVATE SECTOR	2
NATIONAL CIVIC ORGANISATIONS	2
PROVINCIAL HEALTH DEPARTMENTS	9 (only seven visited; all invited)
OTHER GOVERNMENT DEPARTMENTS	5
PARLIAMENTARY COMMITTEES	1

Organisations	Number
EXTERNAL FUNDING AGENCIES	13 (NOT VISITED BUT INVITED)
TOTAL ORGANISATIONS IDENTIFIED	95

Issues discussed with stakeholders included the appropriateness of ENHR as a strategy in South Africa, comments and concerns on the ENHR task team report and workshop recommendations and on the need for a prioritisation Congress.

Despite some concerns regarding the impact of prioritisation on funding, there was a general consensus that prioritisation of health research was a necessary step towards implementing the ENHR strategy.

3. PRIORITY SETTING

3.1. The aims of the congress

The aims of the Congress were to:

* identify health research areas that address priority health problems

* develop a process for consensus building

* facilitate the establishment of and ENHR Committee

An ENHR working group was established in September 1996 to assist in the development of the criteria and process of prioritisation. The working group was composed of representatives of the MRC, the Human Sciences Research Council (HSRC) the HST, the Medical Association of South Africa (MASA) and the DOH.

3.2. Criteria for prioritisation

The underlying assumptions of the prioritisation process was that it should lead to consensus building among producers of research and users of research results, which is more important than the specific list of priorities, since the research tasks will evolve continuously as the changes occur in economic, social, demographic and environmental conditions.

The development of the process and criteria was based on the principle of attaining equity in health and development and the recommendations of the task team and February workshop participants, which were outlined in the DOH document, TOWARDS A NATIONAL HEALTH SYSTEM [(4)].

The criteria were based on the use of both **quantitative** and **qualitative** data and included:

* Community perceptions
* Health status
* Burden of disease
* Unmet health care needs
* Availability of current interventions
* Amenability of a given condition to interventions

The criteria and guidelines of the WHO ad hoc Committee for Health Research in Development[5] and similar priority setting exercises in Uganda and Zimbabwe were also used in the development of criteria for the South African process.

Prioritisation was designed as a stepwise process and is outlined in Figure 1.

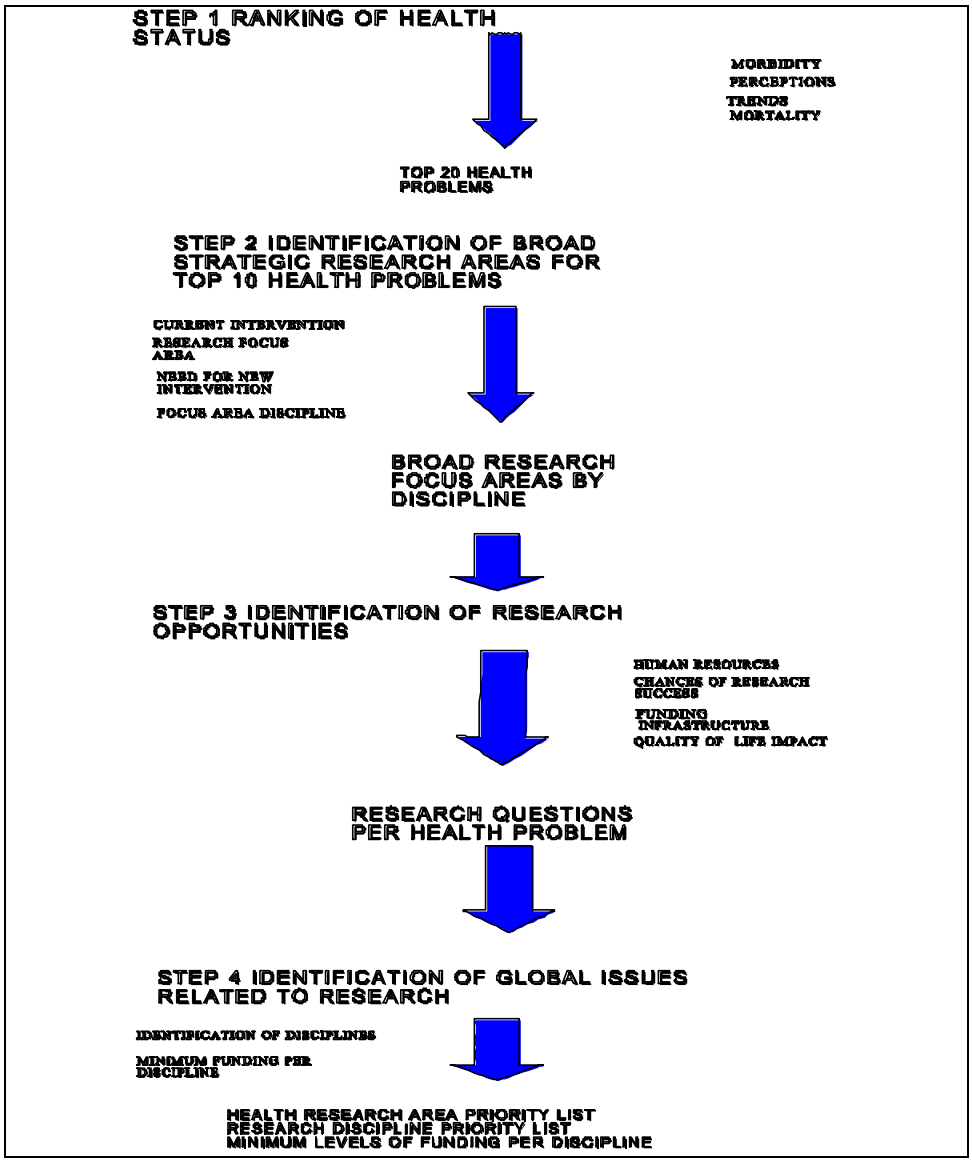

FIGURE 1. PROCESS AND CRITERIA FOR PRIORITISATION

Facilitators were drawn from NGO's, professional bodies, Universities and the Science Councils and were fully briefed on the process. The plenary facilitator was chosen on the basis of extensive previous experience with the ENHR process and a non-vested interest in the South African process.

3.3. Congress participants

Two representatives of all organisations and institutions, and three representatives of government departments were invited to the Congress. Of those organisations invited, a total of 77 (81%) were represented at the Congress. These included Universities, Science Councils, NGO's, international funding agencies, Provincial health departments, other government departments and the private sector.

4. CONGRESS PROCEEDINGS

4.1. STEP 1: Ranking of priority health problems/disease

The major health problems were ranked on the basis of four criteria:

4.1.1. Mortality

Mortality data were presented jointly by the MRC and the Central Statistical Services (CSS). These data were presented in order to provide an objective measure to the prioritisation process. A summary of the top 20 causes of mortality in South Africa for 1990 and 1994 were presented in Table 1, Annex 1. This table also indicates the ranking of the causes of death.

4.1.2. Morbidity and Years of Potential Life Lost (YPLL's)

Morbidity data was based on hospital discharge rates. Table 2, Annex 1 represents the percentage estimated YPLL's for South Africa for 1990 and 1994.

4.1.3. Trends in disease profile

The Department of Health presented the data on health status trends, which provided the opportunity to take into account the importance of specific conditions that are in the early phases of an epidemic.

4.1.4. Perceptions of participants

The vast experience of the participants and the perceptions for the community were also used as a criterion for prioritisation.

4.1.5. Method for ranking priority health problems

Participants were randomly allocated to 10 working groups, after the plenary session, and were asked to rank the top 20 health problems based on the four criterion.

Each participant in a work group was asked to reassess their choice of the top 20 diseases after a period of discussion within the working group. The discussions included identification of the obvious gaps in the identified diseases and clarification of diseases versus cross-cutting issues.

At the end of the discussion period, the facilitator was tasked with compiling a group vote based on inverse score ranking of the total votes per health problem area, per working group.

4.1.6. Results of Step 1

Table 2 CONGRESS IDENTIFIED PRIORITY HEALTH PROBLEMS

DISEASE/ HEALTH PROBLEM	TOTAL SCORE	DISEASE/HEALTH PROBLEM	TOTAL SCORE
INJURY /TRAUMA/ VIOLENCE(INCL RAPE)	1713	EDUCATION	154
TB	1589	SANITATION	149
NUTRITION	**1501**	CHILD HEALTH	148
HIV/ AIDS	1224	LIFESTYLE	119
STD'S	1198	ASTHMA	112
CANCER (ALL)	1123	CAPACITY BUILDING	111
DIARRHOEA	1051	GERIATRICS	110
RESPIRATORY INFECTION (INCL. COAD)	777	ARTHRITIS	98
MENTAL HEALTH (EXCL. SUBSTANCE ABUSE)	685	PHYSICAL DISABILITY	93
MALARIA	657	ORAL HEALTH	86
DRUG ABUSE	620	ENVIRONMENTAL EXPOSURE	76
CARDIO-VASCULAR DISEASE	570	CLINICAL AND EXPERIMENTAL RESEARCH	70
DIABETES	459	ANAEMIA	70
HYPERTENSION	382	INFANT MORTALITY	68
MEASLES	328	MOLECULAR BIOLOGY	62
TEENAGE PREGNANCY	313	PARASITIC DISEASE	54
PERINATAL MORTALITY	283	TRADITIONAL MEDICINE	40
NON- INTENTIONAL INJURY	276	IMMUNISATION	38
SMOKING	233	SAFE MOTHERHOOD	32
HEALTH SYSTEMS	250	HEPATITIS	29
WOMEN'S HEALTH	229	HEALTH INFORMATION	22
OCCUPATIONAL INJURY	182	RENAL DISEASE	21
EMERGING INFECTIOUS DISEASES	175	AGEING	20

4.1.6.1. Discussion Step 1

The composite ranking of health status by Congress participants includes broad categories, risk factors and other issues that would support a research environment or research discipline. An analysis of the disease conditions only, indicates a strong concurrence between diseases ranked by mortality and morbidity and those ranked by Congress participants.

Comparative analysis between Congress ranked priorities and ranking by YPLL show a poor correlation(Table 3). This would indicate that participants had used other criteria such as trends and perceptions to modify the list. However, Congress priorities reflect those health priorities identified by the Reconstruction and Development Pro-

gramme (RDP) (Table 3). This could mean that participants had been primed by these priorities or it provides a validation of the RDP Health priorities. The only priority area that does not coincide between the two lists is that for injury/violence, as this category is not defined in the RDP. Injury / violence is however a major consideration in the Government's Growth and Development Plan.

The appearance of broad categories in the list made the process of prioritisation more difficult. For example, Cancer was proposed as a health problem. An analysis of individual participants recommendations, indicates that the areas of concern within the category of cancers were confined to 3 or 4 specific conditions and not all 207 cancer types. (See Table 4)

A similar situation arises in trying to prioritise risk factors. With respect to poverty as a category, the areas of interest would be extremely broad. For example, the focus of research could be on general policy analysis, health economics or macro economics. Among these broad categories, the focus needs to be further refined and identified, perhaps as macro economics.

An analysis of research questions in Tables 5-8 illustrates that broad categories and risk factors emerge from the research questions. Within the broad category of HIV/AIDS, one of the research questions identified was the socio-economic impact of the disease; this particular research question forms an integral part of the poverty risk factor category.

The positive aspect of identification of health problems by broad categories and risk factors, is that these are often used by communities and social scientists as opposed to medical oriented researchers to identify priorities, and their appearance within the priority list is a reflection of the composition of participants at the congress.

TABLE 3: COMPARISONS BETWEEN TOP 10 HEALTH CONDITIONS AS RANKED BY YPLL ESTIMATES FOR 1994 , CONGRESS PARTICIPANTS 1996 AND THE RDP

CONDITION	CONGRESS RANK 1996	YPLL RANK 1994	RDP PRIORITY
INJURY(all causes)	1	1	NO
TB	2	5	YES
NUTRITION	3	8	YES
HIV/AIDS	4	NOT RANKED IN TOP 10	YES
STD'S	5	NOT RANKED IN TOP 10	YES
CANCER	6	NOT RANKED IN TOP 10	YES
DIARRHOEA	7	3	YES
RESPIRATORY INFECTION	8	4	NO
MENTAL HEALTH	9	NOT RANKED IN TOP 10	YES
MALARIA	10	NOT RANKED IN TOP 10	NO

CONDITION	CONGRESS RANK 1996	YPLL RANK 1994	RDP PRIORITY
SEPTICAEMIA	-	10	YES
PERINATAL CONDITIONS	-	2	YES
STROKE	-	6	YES
IHD	-	7	YES
DIABETES	-	9	YES

TABLE 4 SPECIFIC ISSUES AND CONDITIONS IDENTIFIED WITHIN BROAD CATEGORIES BY CONGRESS PARTICIPANTS

MENTAL HEALTH - Depression and suicide - PTSD - anxiety - disabilities - attention deficit disorder - Substance abuse - alcohol - smoking - other	NUTRITION - undernourishment - overnourishment(incl obesity) - malnourishment - micronutrient deficiency - breastfeeding - nutrition surveillance	CARDIOVASCULAR DISEASE - circulatory - Ischaemia - Hypertension - stroke - other heart disease	CHILD HEALTH - measles - perinatal mortality - infant mortality - congenital anomalies - abuse - nutrition - respiratory infection - diarrhoea
2. CANCERS - cervix - breast - lung - oesophagus - AIDS related - liver	RESPIRATORY DISEASES - ARI - COPD - Asthma - URI - COAD - Pneumonia - Influenza - Diptheria - Streptococcal infection - Meningococcal infection	ENVIRONMENTAL FACTORS - access to health services - lack of housing - lack of water and sanitation - increased urbanization - air pollution - poverty - population development	
INJURY - domestic and interpersonal - traffic - occupational - child abuse - trauma - poisoning - violence(women, children and other)	WOMEN'S HEALTH - teenage pregnancy - mental health - anaemia - breastfeeding - maternal health care and Safe Motherhood - abortion - osteoporosis - hyperthyroidism - fecundity - cervical cancer - breast cancer	INFECTIOUS DISEASES -HIV -STD'S -Hepatitis -measles -TB -Malaria -Diarrhoea -Typhoid -polio -Drug resistance	
OCCUPATIONAL HEALTH - accidents - asbestosis - injuries - diseases - agricultural poisoning	DISABILITIES - general - hearing - senility - vision - child disabilities - physical - Alzheimer	GERIATRICS - senility - arthritis - osteoporosis - endocrine disorders	

Pre Congress priorities

Prior to the Congress, invited organisations were asked to submit a list of their current priorities and ANNEX 2 indicates a summary of the pre-Congress priorities of a limited number of organisation. A total of 23 organisations consisting of 5 Science councils, 5 Universities, 3 NGO's, 2 Parastatals, 4 provincial DOH's and 4 Professional Organisations responded to the questionnaire.

This table indicates some degree of correlation between priorities identified prior to the Congress, by some organisations, and those priorities determined at the Congress. It is interesting to note however, that TB which was identified as the 2nd most important disease condition for priority research, by Congress participants, is studied only by 2 organisations as a priority in the pre Congress priority list in comparison with STD's (which was ranked 5th by Congress participants) which is studied by 12-14 organisations. This data has however to be interpreted with caution since the organisations that responded to the questionnaire for pre-Congress priorities were not representative of the entire spectrum. Where correlation between the pre and post Congress lists is found, this may only reflect the bias of organisations that attended the Congress.

4.2. STEP 2: Identification of broad research areas

4.2.1. Method for Step 2

An attempt was made to identify broad research areas within the " TOP 10" diseases. This exercise was not meant to endorse the TOP 10 diseases but should be seen as an attempt to identify broad research areas. A similar exercise is needed for the other priority health problems identified.

Participants were self-assigned to "expert groups" based on interest in a specific topic. Seven expert groups were asked to consider the following questions in the determination of their broad research areas :

4.2.2 Criteria for Step 2

1. What are the current interventions available to address the problem?
2. Are these interventions successful?
3. In which way are these interventions not successful?
4. Is a new intervention indicated?
5. What type of research is required for the "new" intervention , by discipline?

4.2.3. Results Step 2

The groups identified the detailed research questions in Step 2, which should have been identified in Step 3. The results presented here indicate that participants saw the separation of steps 2 and 3 as been an artificial divide and would see these two steps as a single step.

Despite the amalgamation of step 2 and Step 3 by participants, the objective of obtaining a PRELIMINARY list of research questions by consensus, from participants of various backgrounds, was encouraging, and did achieve the Congress aim of consensus building.

Prioritisation on a problem oriented basis indicates a need for a variety of different in-

terventions to achieve equity in health, which endorses a holistic approach to health research.

The detailed results of Step 2, which identify the broad research areas by discipline, are presented in Tables 5 - 8. NOTE: A number of the research questions outlined in the tables, can be classified into one or more research type categories; and these research types should not be seen as watertight compartments.

TABLE 5: BROAD RESEARCH QUESTIONS BY DISCIPLINE FOR STD'S/HIV/AIDS, TB AND MALARIA

DISEASE CONDITION RESEARCH TYPE	HIV/AIDS	TB	MALARIA
BASIC RESEARCH	1. Rapid test 2. Congenital STD detection 3. Syndromic treatment 4. Asymptomatic detection	1. Rapid disease diagnosis 2. Detection of MDR 3. Detection in children 4. Detection of re-infection vs reactivation 5. Determination of specimen quality 6. Identification of BCG strains for vaccine development 7. Identification of individual susceptibility	1. Development of appropriate diagnostic guidelines 2. Identification, behaviour and susceptibility of vectors 3. Outbreak predictions 4. Improved diagnostics for malaria
CLINICAL RESEARCH	1. Congenital STD Detection 2. Syndromic Treatment 3. HIV Treatment 4. Vaccine Development 5. Vertical transmission drug development	1. Alternative drug delivery systems 2. BCG vaccine efficacy	1. Efficacy, acceptability and type of therapy and prophylaxis
SOCIAL SCIENCES	1. Condom usage 2. Asymptomatic detection 3. patient behaviour 4. health worker issues 5. Vertical Transmission 6. Socio-economic impact assessment	1. Identification of environmental and social determinants of disease	1. Increase in community co-operation with malaria control programmes
HEALTH SYSTEMS, PUBLIC HEALTH AND POLICY RESEARCH	1. Policy development and evaluation 2. Socio-economic impact assessment 3. Models of care 4. Asymptomatic detection 5. Health worker issues 6. Post exposure prophylaxis 7. Ethical legal issues	1. Identification of Environmental risk factors 2. Feasibility of on site treatment 3. Improved information systems 4. Systematic review of efficacy 5. Case holding patterns 6. Identification of service organisations	1. Efficacy, appropriateness and quality of surveillance systems 2. Appropriate diagnostic guidelines 3. Health care workers attitudes to identification and treatment 4. Outbreak prediction 5. Cross border control of malaria

TABLE 6 : BROAD RESEARCH QUESTIONS BY DISCIPLINE DIARRHOEA AND RESPIRATORY INFECTIONS

DISEASE CONDITION RESEARCH TYPE	DIARRHOEA AND RESPIRATORY INFECTIONS	ACUTE RESPIRATORY INFECTION	INFECTIOUS DIARRHOEA
BASIC RESEARCH	1. Vaccine Development for HiB, Measles and pneumonia 2. Identification of antibiotic resistance	1. Identification of resistance factors in ARI	1. Aetiology and strain identification 2. Methods for the detection of Rotavirus and routes of transmission 3. Diagnostic indicators to distinguish between osmotic and secretory diarrhoea 4. New test kits
CLINICAL RESEARCH	1. Interaction of infectious agents with predisposing illness 2. Improved compliance 3. Vaccine effectiveness	1. Effectiveness of chemotherapy 2. Clinical trials on pneumococcal vaccines	1. Rotavirus vaccine testing 2. Cost effectiveness of Rotavirus vaccine 3. Monitoring vaccine efficacy and standards
SOCIAL SCIENCES RESEARCH	1. Identification of lifestyle risk factors 2. Identification of factors for compliance with therapy	1. Identification of ARI risk factors: housing, overcrowding, pollution	1. Identification of lifestyle risk factors: housing and sanitation
HEALTH SYSTEMS, PUBLIC HEALTH AND POLICY RESEARCH	1. Pollution avoidance 2. Risk factor identification 3. Assessment of vaccine cost, accessibility, availability and effectiveness	1. Identification of ARI risk factors 2. Cost effectiveness of chemotherapy	1. Cost effectiveness of Rotavirus vaccine 2. Evaluation of Oral Rehydration therapy 3. Effective systematic reviews 4. Monitoring of vaccine efficacy and Standards

TABLE 7 : BROAD RESEARCH QUESTIONS BY DISCIPLINE FOR NUTRITION AND CANCERS

DISEASE CONDITION RESEARCH TYPE	NUTRITION	CANCERS
BASIC RESEARCH	1. Food Safety 2. Bioavailibiltiy of nutrients 3. Malabsorption 4. Competing nutrient demands	1. Improved detection of aetiology
CLINICAL RESEARCH	1. Interaction between substance abuse and nutritional status 2. Development of nutritional status assessment methods	1. Risk factor identification for oesophageal cancers 2. Effectiveness of cervical cancer treatment
SOCIAL SCIENCES RESEARCH	1. Food security KAP study 2. Food accessibility 3. Food security education and capacity development	1. Development of cancer prevention strategies
HEALTH SYSTEMS, PUBLIC HEALTH AND POLICY RESEARCH	1. Prevalence rates of nutritional disease 2. Development of nutritional status assessment methods 3. Impact of programme implementation 4. Development of monitoring tools 5. Interaction between substance abuse and nutritional status	1. Improved surveillance system for identification of incidence and prevalence 2. Effectiveness of cervical cancer screening programmes 3. Cost utility studies of interventions based on length of life, QOL and financial meta-analyses

TABLE 8 : BROAD RESEARCH QUESTIONS BY DISCIPLINE FOR MENTAL HEALTH AND VIOLENCE/INJURIES

DISEASE CONDITION RESEARCH TYPE	MENTAL HEALTH	VIOLENCE
BASIC RESEARCH		
CLINICAL RESEARCH	1. Identification and management of mental health problems among health care workers	1. Cost effectiveness of clinical management of injury from violence
SOCIAL SCIENCES RESEARCH	1. Development of interventions for the integration of the disabled 2. Development of culturally appropriate intervention 3. Counselling skills for Health Care workers 4. Development of community based interventions	1. Resource needs of the criminal justice system to decrease injury rates 2. Training and sensitising police in dealing with injury
HEALTH SYSTEMS, PUBLIC HEALTH AND POLICY RESEARCH	1. Development of community based interventions 2. Incidence of teenage suicide 3. Integration of mental health into PHC 4. Integration of traditional healers into the Mental Health Services 5. Economic impact of Mental Health on the society	1. Integrated intersectoral pilot programmes - Use of trauma centres as a site for police presence - Impact of education and recreational facilities on sexual abuse and violence among youth 2. Training of HCW to deal with injuries 3. Effectiveness of compensation system for all injuries 4. Economic and social impact of injuries 5. Development of cost effective management interventions for dealing with injuries and violence 6. Legislation effectiveness 7. Development of a surveillance system and strategies for injury and violence prevention and legislation implementation

4.3. STEP 3: Discipline specific priorities

4.3.1 Method and criteria for step 3

Several issues of concern were raised by Congress participants prior to the implementation of step 3. Participants indicated that it would be more useful if 4 groups were formed to discuss crosscutting issues of concern for each research discipline viz.,

1. Social and Behavioural Sciences
2. Basic Research
3. Health Systems Research
4. Clinical Research

4.3.2. Results STEP 3

The results of the modified step 3 are indicated below in Table 9.

The group discussions did not relate to identifying research discipline priorities, but dealt with the general importance of each discipline, and the environment that would enable research to be conducted viz., issues of capacity building, funding and infrastructure.

For example, the social and behavioural sciences group indicated that social sciences research needs to be undertaken for all health problems. The importance of social sciences research did emerge from Step 2, but more importantly, specific questions around priority health problems were also identified; which was not the case with discipline specific working groups.

TABLE 9 : DISCIPLINE SPECIFIC PRIORITIES AND CONCERNS

CLINICAL RESEARCH WORKING GROUP	BASIC RESEARCH	SOCIAL AND BEHAVIOURAL SCIENCES	POLICY AND OPERATIONS RESEARCH
1. The Research priorities of clinical research need to focus on : * Nutrition * HIV/AIDS * Diarrhoea *TB * Cancer * Mental Health * Malaria * Violence and Injury 2. Identification of researchers to accomplish the indicated research 3. The role identification of various institutions 4. Identification of strategies to build clinical research capacity	1. Allocating only 8% of the total research budget on Basic Research would be an under-investment since there is a strong current biotechnology base which focuses on long term solutions. 2. The development of appropriate, rapid and cost-effective : - diagnostics - Therapies - Prophylaxis 3. Determining individual susceptibility 4. Understanding pathogenesis 5. Development of molecular epidemiology 6. Development of vaccinology - vaccine development - vaccine evaluation - vaccine delivery	1. Integration and equitable funding for behavioural specialities in the health service 2. Demedicalisation of the approach to health problems 3. Behavioural research needs to be undertaken in all the priority health problem areas.	1. Economic analyses of policies and programmes 2. Identification of appropriate methods for evaluation and monitoring 3. Development of criteria for the allocation of resources 4. Identification of strategies to improve inter-sectoral collaboration 5. Identification of strategies for community participation in health service delivery 6. Systematic reviews of effectiveness of interventions 7. Identification of strategies to improve quality of services 8. Impact assessment of poverty and inequality interventions on the health sector 9. Strategies for funding non-traditional research areas. 10. Develop strategies to integrate national and provincial priorities 11. Evaluation of Research co-ordination 12. Needs analysis for surveillance systems 13. Monitoring strategies for research 14. Formal allocation within research proposals for cost utility of a study

			15 Targeted research training for service providers within institutions 16. Develop a funding structure that is co-ordinated but not centralised

4.3.3. Discussion of concerns raised by participants

The issues of concern raised by participants are discussed below.

** Prioritising the next 10 priority areas rather than developing the questions.*

The point of the Congress was to identify the research needed for the priority problems and with the limited time it was decided to concentrate only on the TOP 10. However, expert groups will be established to look at the other health problems identified and to develop research questions for these problems.

** The prioritisation process was not concentrating on future need*

Based on the health trends information, it was expected that priorities for the future would be identified by participants. The results clearly indicate that issues such as injury and chronic diseases were identified as priorities

** Issues such as capacity development , funding and networking were not identified within the prioritisation process and need to be addressed.*

Cross cutting issues such as the above-mentioned, are Management issues and form part of the ENHR strategy's other elements. This Congress was aimed at prioritising research questions only, and a concerted effort to promote other ENHR elements will need to be made by the ENHR Committee

** the Congress participants did not reflect the entire spectrum of researchers to develop detailed research questions*

It has been discussed that expert groups will need to be established to take the prioritisation process to completion.

** there was no clarification on the distribution of funds and it would be necessary to identify the resource status for these four identified areas of research*

Funding of health research is another element of the ENHR strategy and will need to be discussed and planned for, by the ENHR Committee. The identification of the resource status would be a function of the ENHR Committee and it would be non-productive to pre-allocate funds within a needs based prioritisation framework.

** the disease groupings were inadequate as a basis for prioritisation*

Both the task team and workshop participants as well as the document "Towards a National Health System" recommend the use of burden of disease as a basis for health research prioritisation

** Provincial priorities need to be integrated into the process*

Provincial and district priorities are an integral part of the prioritisation process.

Some of the concerns highlighted above, for example, the inclusion of provincial priorities, capacity development etc are indicative of a serious lack of understanding of the underlying principles of ENHR and point to a very real and urgent need for advocacy and promotion of ENHR.

Other concerns expressed such as the use of a quantitative ranking systems, and identification of resources etc will need to be taken up by the ENHR committee for future planning purposes.

5. CONCLUSIONS

South Africans from different spheres of life, but with an interest in the health of South Africans, generated a set of health priority problems that need the attention of researchers in the country.

The Congress therefore achieved its aim of the establishment of a preliminary list of priority health problems and urgent research questions, more importantly the Congress achieved this through consensus and participation of basic scientists, clinical researchers, administrators, health service providers, funders and representatives of professional associations.

The Congress also provided an insight into the prioritisation process to participants, and it is hoped that the collective wisdom of the Congress would be used in the ongoing refinement of the process.

6. THE WAY FORWARD

6.1. The Prioritisation Process

Based on the recommendations of the task team, the February workshop and Congress participants, the priority areas identified will be :

* sent for review to the ENHR committee

* sent to expert groups for verification and extension

* discussed with communities representative, provincial and local level departments for validation of priorities

* The priority list should be used by organisations in setting their research priorities

6.2. Establishing the ENHR mechanism

In terms of the ENHR Committee the recommendation made by the task team , the workshop and Congress participants will be forward through:

* Nominations for members to the Committee will be solicited from major stakeholders of the ENHR process and will be appointed by the Minister

* The Committee's terms of reference will be established within the framework of the ENHR strategy.

* The ENHR Committee will develop the more detailed strategic plans for the ENHR process in South Africa, taking into account the concerns expressed by Congress participants.

7. CONGRESS EVALUATION

Congress evaluation questionnaires were given to all participants as part of their Congress package and re-faxed to all participants after the Congress. Despite the great emphasis placed on Health Systems Research by Congress participants, disappointingly, only 34 of 160 (21% of participants) responded by returning their evaluation forms. The Evaluation results are presented in Annex 3.

A review of these evaluation results supports the idea that an intensive effort is needed to promote ENHR among the role players. For example, a combined 29% of respondents identified the weakness of ENHR to be a lack of evaluation, capacity building etc; all of which are part of the ENHR process.

Furthermore, the results clearly indicate that many participants may not have read the background material sent to them prior to the Congress. There also seems to be conflict with the number of role players that need to be included, and this clearly indicates that the consensus building process needs to be further addressed.

ANNEX 1

TABLE 1 : TOP 20 CAUSES OF MORTALITY IN SOUTH AFRICA - 1990 AND 1994

DISEASE	PERCENTAGE MORTALITY 1990 (RANK)	PERCENTAGE MORTALITY 1994 (RANK)
ILL DEFINED	16.55 (1)	15.2 (2)
STROKE	7.35 (2)	7.0 (3)
SENILITY	6.86 (3)	UNRANKED
PERINATAL CONDITIONS	6.21 (4)	3.5 (6)
IHD	4.86 (5)	4.4 (4)
URI	4.83 (6)	4.3 (5)
TB	4.72 (7)	UNRANKED
DIARRHOEA	3.84 (8)	2.5 (9)
UNINTEN INJ	3.22 (9)	INCL IN ALL INJURIES
UNINTEN INJ (UKC)	3.14 (10)	INCL IN ALL INJURIES
DIABETES	2.60 (11)	3.3 (7)
COPD	2.44 (12)	2.1 (12)
CANCER LUNG	2.02 (13)	1.7 (14)
OTHER CVD	1.95 (14)	2.3 (10)
INTENTIONAL INJ	1.81 (15)	INCL IN ALL INJURIES
PULM CIRC	1.74 (16)	1.4 (15)
SEPTICEMIA	1.63 (17)	1.5 (14)
NUTRITION/ENDO	1.63 (18)	1.0 (18)
OTHER NEOPLASMS	1.61 (19)	2.7 (8)
CANCER ESOPH	1.52 (20)	1.2 (17)
ALL INJURIES	-	19.2 (1)
OTHER RESPIRATORY	-	1.0 (19)
OTHER DIGESTIVE	-	0.8 (20)

TABLE 2 : INVERSE RANKING OF ESTIMATED PERCENTAGE YPLL IN SOUTH AFRICA 1990 AND 1994

Disease/Condition	PERCENTAGE Esti-mated YPLL in South Africa 1990(DALY WEIGHTS)	DISEASE/ CONDITION	PERCENTAGE ESTIMATED YPLL IN SOUTH AFRICA 1994 (DALY WEIGHTS)
CA OESOPHAGUS	1.19	OTHER DIGESTIVE	0.6
NEPHRITIS	1.28	ASTHMA	0.7
PULM CIRCULATION	1.36	OTHER RESPIRATORY	0.76
CA LUNG	1.46	EPILEPSY	0.85
OTHER CARDIOVASCULAR	1.48	NEPHRITIS	0.89
COPD	1.5	OTHER CVD	0.91
SENILITY	1.58	DIABETES	1.05
SEPTICAEMIA	1.78	IHD	1.05
DIABETES	1.81	MENINGITIS	1.08
NUTRITION/ ENDOCRINE	2.46	SEPTICEMIA	1.65
INTENTIONAL INJURY	2.87	CONGENITAL	1.82
IHD	2.88	STROKE	2.16
STROKE	4.75	NUTRITIONAL/END	2.23
UNINTENTIONAL INJURY	4.76	OTHER NEO	3.38
INJURY (CA USE NOT KNOWN)	4.84	TB	4.38
TUBERCULOSIS	5.17	URI	5.13
UPPER RESP INFECTION	5.24	DIARRHOEAL	6.43
DIARRHOEA	6.37	ILL DEFINED	11.34
PERINATAL	11.49	PERINATAL	11.66
ILL-DEFINED	16.76	UNIT/INT INJ	31.93

SOURCE: COURTESY OF DEBBIE BRADSHAW ,MRC

ANNEX 2

TABLE 1 : PRE-CONGRESS PRIORITIES IDENTIFIED BY DIFFERENT ORGANISATIONS

Priority Areas	Number of Organisations indicating this category	Priority Areas	Number of Organisations indicating this category	Priority Areas	Number of Organisations indicating this category
Mental Health		Drug Management		Nutrition	
- substance abuse	6	- drug handling	3	- land reform	1
- mood disorders	2	- EDL	3	- malnutrition	7
-schizophrenia	1	- Efficacy	1	- undernutrition	1
- anxiety	1	- patient compliance	1	- paediatric	1
- suicide	2	- quality control	3		
HRD (Incl Capacity Development)		Infectious diseases		Child Health	
		HIV/AIDS	8	- Child abuse	3
- Training of researchers	4	STD's,	10	- malnutrition	6
- Community participation		Diarrhoea,	2	-diarrhoeal disease	3
- Training of pharmacists	2	Respiratory	3	- infant mortality	2
-HBU/HAU linkages,		TB,	6	- immunisation	1
- Nursing education	1	malaria,	2	- HIV/STD's	2
- Technology development		Hepatitis	3	- Homeless and crisis management	2
	2	Pneumococcal disease	2		
	2				
	1				
Information systems		sustainable development	1	Trauma and disability	6
- demographic	2			- Community based care	1
- health trends	1				
- disease based	5			- medico-legal	2
-research database	1				
Chronic and degenerative diseases		Cancers		Environmental Health	
		- breast	2	- service provision	2
- ageing	1	- lung	2	- water and sanitation	2
- lifestyle		- cervix	4		

	2		- oesophagus - paediatric -liver - surveillance	2 1 2 3			

TABLE 1 CONTINUED.....

Priority Areas	Number of Organisations indicating this category	Priority Areas	Number of Organisations indicating this category	Priority Areas	Number of Organisations indicating this category
Women's Health - cervical and breast cancer - spousal abuse - pre-eclampsia - feto maternal medicine - nutrition - contraception - anaemia - teenage pregnancy - abortions - maternal mortality - HIV/STD's/TB - rape	2 8 3 1 1 1 3 2 4 1 2 1 1	Cardiovascular Disease - Hypertension - Rheumatic Heart Disease -IHD	3 3 1 1	Violence and Injury - surveillance - traffic - assault - drug related - homicide - gangsterism	2 1 3 1 1 2 1
Financial Management	3	Vaccine procurement	2	Ethics	1
Oral Health	3	restructuring of the health care system	4		

ANNEX 3

CONGRESS EVALUATION

TABLE 1: CLEARNESS AND APPROPRIATENESS OF CRITERIA

1. Were criteria clear and appropriate?

Yes/No	Number of respondents(%) N=34
Yes	17 (50%)
Incidence of disease not taken into consideration	1(3%)
Too subjective to use perceptions	3(9%)
Not enough participants with more personal knowledge	1(3%)
Criteria did not address Health Systems Research issues	1(3%)
criteria not comprehensive enough, need to include cost effectiveness	1(3%)
Criteria were not made clear enough	3(9%)
need to discuss these and use public perceptions as well	2(6%)
no answer	2(6%)
needed to discuss the other diseases as well	1(3%)
Did not address effectiveness of research	1(3%)

TABLE 2: CLEARNESS AND APPROPRIATENESS OF PROCESS

2. Was the stepwise process clear and appropriate?

Yes/No	Number of respondents N=34
Yes	17(50%)
Use Delphi technique to obtain a pre-Congress priority list	1(3%)

Yes/No	Number of respondents N=34
Congress priorities may be quantitated and used for funding	2(6%)
Need to discuss the stepwise process further	5(15%)
need to identify other health problem categories which do not appear on DALY's	1(3%)
no answer	2(6%)
Not explained clearly	1(3%)
too detailed, needed to stop with some research areas only	1(3%)
some of it was clear	1(3%)
too many non-experts to use the criteria effectively	1(3%)
broke down on second day	2(6%)

TABLE 3: APPLICABILITY OF ENHR STRATEGY IN SOUTH AFRICA

3. What do you think of the ENHR strategy in South Africa

RESPONSES	# OF RESPOND. (%) N=34
It allows representivity of all disciplines and sectors	3(9%)
no answer	1(3%)
Needs to be implemented correctly	6(18%)
allows needs based planning for research	8(24%)
Appropriate	10(29%)
allows a framework for a change in mindset towards health research	2(6%)
Can be threatening to researchers not involved in priority re-search	1(3%)
will ensure co-ordination	2(6%)

TABLE 4: STRENGTHS OF ENHR

4. What are the strengths of ENHR?

RESPONSES	NUMBER OF RESPONDENTS (%) N=34
will allow the development of a policy on health research	1(3%)
Consensus building: Inclusivity, representivity, transparency	17(50%)
no answer	3(9%)
prevents duplication/facilitates co-ordination	4(12%)
facilitates prioritisation and resource allocation	7(21%)
unaware of the strategy/no comment	2(6%)
country needs based	6(18%)
Evaluation	1(3%)

TABLE 5: WEAKNESSES OF ENHR

5. What are the weaknesses of ENHR?

RESPONSES	NUMBER OF RESPONDENTS(%) n=34
Too many role players with their own agendas	5(15%)
Not enough role players	10(29%)
No answer	3(9%)
Not academic enough (marginalisation of the professionals opinion)	1(3%)
no provincial priorities	2(6%)
Too academic	1(3%)
No evaluation, networking or capacity building, issues of funding not addressed	6(18%)
Not strategic enough/no link technology development/ too PHC focused	7(21%)
Too structured	1(3%)