

**THE SETTING OF HEALTH RESEARCH PRIORITIES
IN SOUTH AFRICA**

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ABSTRACT

The health and development of a nation are linked. Health research is a vital element helps bring about improved health and has the potential to serve as an impetus for equitable development. Generally it is necessary to prioritise needs in order to optimise the use of scarce resources for development.

The overall aim of this thesis is an analysis of the setting of health research priorities, with specific reference to South Africa. Other objectives include describing the technical approaches used for priority setting and developing a suitable framework for analysing and classifying health research. Two other objectives concern measurement for priority setting: Specifically, how burden of disease quantification fits into the process of priority setting and a thorough critique of the Disability Adjusted Life Expectancy (DALY). Another objective was to examine priority setting and Essential National Health Research (ENHR) in the South African context. A further important objective is the development of a framework for guiding the analysis of health research priorities. This framework is part of model for health research priority setting that incorporates ENHR strategy and burden of disease methodology.

The methods used ranged from an extensive literature review to statistical analysis. The literature review included grey literature and draws on multiple disciplines such as economics, public health policy and economics.

At the global level there is gross mis-allocation of research funding. Less than 10% of global health research spending is devoted to 90% of the global burden disease. In response to this distortion, the global initiative to promote Essential National Health Research (ENHR) in developing countries calls for the setting of national health research priorities.

Prioritisation can be examined from a health problem, a target group, a broad intervention or a systems perspective. These approaches, however, merely generate lists of health

research needs and do not prioritise them. The literature suggests various criteria that can be used for ranking which include equity, efficiency and sustainability. These criteria represent the values held by the decision makers in a multi-level process. Increasingly, these criteria are being made explicit.

The framework that is provided for the classification and analysis of health research is invaluable for the prioritisation process. It serves as a basis for an audit of ongoing health research and to help specify priorities for future research.

The Ad Hoc Committee of the World Health Organisation was formed to address priorities for health research and development. The burden of disease was analysed in order to assess research needs. The Ad Hoc Committee recently used both a health problem framework and a health systems approach in the review of global research priorities for developing countries. When applying the health problem approach to setting priorities, chosen criteria were combined in a systematic, stepwise manner, thereby making the prioritisation process more transparent, with explicit utilisation of information. A systematic consultation and review process was used to prioritise health policy and health systems research. The criteria for ranking were listed but the weighting of these criteria was not explicit.

A fundamental part of the process of prioritisation involves the choice of the measures to be used to aid decisions on what health research should receive priority ranking. Summary measures of health have not been comprehensively documented. Consequently, a highly relevant contribution for health research prioritisation is the provision of a synopsis of summary health measures and the applicability of these measures for priority setting. These composite measures of mortality and non-fatal health outcomes provide a comprehensive reflection the health status of a population.

The focus in this regard will be to explore the role of the Disability-Adjusted Life Year (DALY) and other associated measures of the burden of disease in prioritising for health

research and development. A detailed critique of the DALY and an examination of the DALY compared with mortality as measures of the burden of disease is presented. The DALE and Life Expectancy are also compared in order to examine the relevance of including non-fatal outcome measures, such as disability, in order to guide the choice of appropriate health research. There is a high correlation between Life Expectancy and the DALE. This indicates that the measure of life expectancy is adequate for describing health status. However, when looking at the burden or health gap, disability is an important component that must be included in order to determine priority health research.

There is a detailed critique of the DALY in terms of the values underlying the measure and the implications of these values for priority setting. The extensive debate over technical and conceptual issues concerning the DALY is used for an applied critique of the DALY and woman's health. In a separate analysis it is shown that the DALY measure does not differentiate the needs of the poor. It is suggested that the DALY can be used to mitigate inequality in health by stratifying data.

An additional important contribution from the thesis is the analysis of the South African situation concerning health research priority setting. South Africa as a fledgling democracy in Africa provides a unique set of circumstances for ascertaining how equity and social justice will be incorporated into all spheres of development.

Until recently there was no national process of prioritisation for health research in South Africa. South Africa is developing an Essential National Health Research Program and a Prioritisation Congress involving all the stakeholders was held in 1996. Influenced by the approach of the Ad Hoc Committee, the congress rapidly assessed the priorities using both a health problem and a health systems approach. The health challenges were identified on the basis of the burden of disease as well as the perceptions of the stakeholders. These are similar to those identified by the Ad Hoc Committee for developing countries. A preliminary list of health research priorities was generated which will serve to

guide health research prioritisation in South Africa. However, substantive analysis and consultation is necessary to distill a specific list of research priorities.

The thesis provides important recommendations for the process of setting health research priorities in South Africa.

There is a need for an urgent and detailed audit of both public and private health research in the country. The audit must include information on both expenditure and a breakdown on the type of research currently being carried out.

Future analysis of health research priorities for South Africa should follow the framework of the Ad Hoc Committee. This framework includes the 5 step approach to identify priority research for health problems and the 3 steps of the health systems approach. It is part of a developing, indigenous model that incorporates burden of disease methodology and ENHR.

It is recommended that a national burden of disease exercise, using a composite measure such as the DALY, be undertaken in South Africa. However, in order to meet the criteria of equity and social justice for priority setting the burden needs to be estimated at sub-population level.

As far as ENHR is concerned, the prioritisation process is unlikely to achieve a meaningful reform of the health research agenda unless accompanied by the implementation of the other elements of ENHR. The South African ENHR Committee should serve to coordinate the elements of ENHR.

CHAPTER 1

SETTING THE CONTEXT FOR HEALTH RESEARCH

1.1 INTRODUCTION

The health of the world's people has improved more in the past four generations than in the whole span of human history. During this time, life expectancy for every income bracket has shifted steadily upwards and a given income buys better health than it did at equivalent levels 30 years ago. The rise in per capita income this century has been closely linked to increases in life expectancy, with the steepest increases occurring at the lowest income levels (Investing in Health Research and Development. Report of the Ad Hoc Committee 1996).

The reasons for these global health improvements as well as the differences both within and between countries are multifarious. According to the World Development Report (WDR): (1993) "These successes, (in the health sphere), have come about in part because of growing incomes and increasing education around the globe and in part because of governments' efforts to expand health services, which, moreover, have been enriched by technological progress" (WDR 1993 P 1).

In addition, scientific research has resulted in technical innovation and improved knowledge about health that has changed peoples' behaviour which has led to improved health status (Investing in Health Research and Development. Report of the Ad Hoc Committee 1996).

While the impact of research is relatively well known, its economic value to society is less widely appreciated (Investing in Health Research and Development, Report of the Ad Hoc Committee 1996). Improved health leads to better utilisation of human capital, increased productivity and it frees up resources that would otherwise be used to treat illness. Also, better health results in improvements in school enrollment and attendance. Good health care is a necessary condition for equality of opportunities and hence is an essential element in the fight against poverty (WDR 1993 and Frenk 1995). Research brings another kind of wealth to society, in that a culture of research provides a rational, knowledge-based framework for progress in health (Investing in Health Research and Development. Report of the Ad Hoc Committee 1996).

Health-care priorities refer to the selection of health services that will be provided first in order to improve health benefits and the distribution of health resources. "Health research priorities, on the other hand refer to diseases, injuries and risk factors that produce a significant burden of disease but lack an effective intervention for their control." (Bobadilla 1996 P 45). Health research priorities also include the investigation of ways of improving the overall effectiveness of health systems.

The 1990 report of the Commission on Health Research for Development (CHRD) entitled: Health Research: Essential Link to Equity in Development, emphasised that for the world's poor, the benefits of research offer a potential for change that has largely gone untapped (Essential National Health Research and Priority Setting 1997). While more traditional views appear to regard research as contributing to a body of knowledge or generating information that may be useful for decision makers, others see it as an instrument used for social and political change by different social groups for different purposes (How to Boost the Impact of Country Mechanisms to Support ENHR 1999). A third perspective is that these views are not seen to be "in opposition to each other but as a spectrum of roles that research plays" (ibid P 15).

A worldwide study of research and development expenditures reported that only 5% of the US \$30 billion global investment in health research in 1986 went to health problems unique to developing countries where an estimated 93% of the world's preventable mortality occurs (Investing in Health Research and Development. Report of the Ad Hoc Committee 1996). Even though the burden of disease is overwhelmingly in the Third World, investment in health research focuses mainly on the health problems of industrialised countries. In the early 1990s, in response to this skewed expenditure in health research, the Commission on Health Research for Development, recommended a strategy of ENHR (ENHR 1991[b]) to aid the reform of health research policy in developing countries (Health Research: Essential Link To Equity In Development 1990).

A 1992 estimate indicates that global spending on health research by the public and private sectors amounts to about US\$56 billion per year. Less than 10% of the global health research spending is devoted to diseases or conditions that account for 90% of the global burden of disease, the so-called 10/90 gap (The 10/90 Report on Health Research

2000). These more recent figures show that the gross mis-allocation of resources with the concomitant human and economic costs, has not been rectified. The Global Forum for Health Research Foundation was established in 1998 with the main objective to help correct the 10/90 gap.

The global epidemic of the acquired immune deficiency syndrome (AIDS) is likely to further exacerbate the existing health differentials between rich and poor countries. It is predicted that the huge gap in human immune deficiency virus (HIV) infection rates and AIDS deaths between rich and poor countries is likely to grow even larger in this century. This differential is particularly pronounced between Africa and the rest of the world. Sub-Saharan Africa continues to bear the brunt of HIV/AIDS with some 23.3 million infected Africans. This amounts to almost 70% of the global total of HIV positive people in a region that is home to just 10% of the world's population (AIDS epidemic update 1999 P 5 and P 14).

The epidemic is particularly severe in South Africa. It is estimated that 3.6 million South Africans are infected with this deadly virus. The HIV epidemic has increased 30-fold since 1980. HIV rates have soared from 0.76% in 1990 to 22.8% in 1998. In particular, there has been a leap in infection rates of young women in the 20-24-year-old age group from about 7% in 1992 to 21% in 1995. One in five young mothers attending antenatal clinics is HIV positive (National Department of Health, April 2000). The United Nations Development Programme has calculated that less than 50% of South Africans currently alive are expected to reach the age of 60. A comparable figure for all developing countries is 70% and 90% for industrialised countries (AIDS epidemic update 1999).

By the year 2005 almost 6 million South Africans could be HIV infected (Dorrington 1999). These statistics reflect not only the enormity of the AIDS epidemic in Sub-Saharan Africa but highlights the need for appropriate health research to address the escalating AIDS problem in desperately resource-poor Sub Saharan Africa (SSA).

1.1.1 POLICY

In general, in the health arena there is a persistent gap between what should be attainable, given the present levels of knowledge, capacity and expenditure and the existing health status quo. Health policy analysis helps understand why appropriate, workable health policies are not affected. Policy analysis is a useful tool for health research and planning, and aids the priority setting process from decision-making and implementation through to evaluation.

Health policy analysis involves the utilisation of health and multi-disciplinary information with analytical skills in interpreting the policy implications of facts and figures and an understanding of the policy process. Policy analysis is important for the setting of health research priorities as it explains the entire process. The prioritisation process includes the politics involved and both are intrinsic for determining what health research is ultimately carried out. "Research policy deals with research processes, the application of findings, research capacity and the decision making processes determining what research is done and how it is supported." (Health Research: Essential Link to Equity and Development 1990).

With evidence-based policy making, policy is only partially driven by data. The focus should not be on health effect only, "but on perceptions, processes, systems and institutions" (Zwi and Mills 1995) According to Lerer (1998 P 7) "Global health policy has to be driven by equity, human rights and gender sensitivity."

When considering the data used for decision-making it must be noted that often health statistics are provided to decision-makers, the scientific community and the public by advocates with their own specific agendas (Murray 1996).

Escalating health costs make the prioritising of health objectives the very basis of national health policy. For this South African study, although there is not a comprehensive and systematic health policy analysis with health research prioritisation a constituent part, the focus is on the latter. However, cognizance must be taken of the underlying political process.

1.2 HEALTH AND DEVELOPMENT

The Constitution of the WHO states that the highest attainable level of health is one of the fundamental rights of every human being (WHO Constitution 1948).

On a global scale there are enormous health problems, especially in developing countries which carry a heavy burden of disease. As early as the twelfth century it was recognized that people at the lowest socio-economic levels in the community have higher death and illness rates (Kaplan *et al.* 1987). The poor - that sector of the population that can least afford to get sick - are the most likely to become ill and once ill, are unable to afford appropriate treatment. This reflects the vicious circle of poverty and ill-health.

This pattern, the correlation between poverty and ill-health, has been observed throughout the world, regardless of whether the major causes of death and disability were from infectious or non-infectious diseases and regardless of how socio-economic position was measured (*ibid*). The most obvious explanations are insufficient medical care, low income, poor nutrition, inadequate housing, lack of sanitation and clean water as well as low levels of education.

Health and development are two closely related phenomena. In numerous respects the development of a society determines the health of the people. The opposite is equally true - the health of people is a precondition for development. Traditional health indicators (e.g. life expectancy, infant mortality rates) are also indicative of the development status of populations and their subgroups (Van Rensburg 1997).

It is generally asserted that economic growth is essential for development. In many countries economic development has contributed to improving the health status of the population. However, certain development strategies may have adverse effects on the health status of certain population groups. For instance, industrialisation and urbanisation can cause ill-health and disease. In addition, some development policies may result in macro-economic adjustments that in turn result in cuts in the health budget of developing countries (Cooper *et al.* 1990).

In the review on the impact of development policies on health, Cooper *et al.* (1990) have identified and classified gaps in research to determine aspects of the relationship between development policy and health that should be prioritized to clarify the research agenda in this area.

Frenk *et al.* (1989) have argued that: “Many of the emerging illnesses are a result of a defective process of industrialization that has placed more value on economic growth rather than on human welfare.”

Health care and the economy are very closely linked. In contrast to other products, health services have a dual character. On the one hand, they constitute an essential component of social development and well-being; while on the other, they represent a growing sector of the economy (Frenk 1995).

There are conflicting views on the role of medicine in development. There are figures that indicate that modern medical care, (based on health research), does not contribute much to the continuing increase in life expectancy in the developed world. A recent estimate, based on the analysis of major medical procedures, including medical forms of prevention, such as screening and immunisations, suggests that the whole modern medical effort adds no more than about five years difference to modern life expectancy (Bunker *et al.* 1994).

McKeown *et al.* (1975) pointed out that the vast bulk of the decline in mortality from infectious diseases came before medicine had effective forms of treatment or immunisation. He argued that this meant the change was not the result of the application of medical science. People remained well because of better nutrition and a healthier environment (McKeown, 1976[a]).

However, McKeown, (1976[b]) recognized some of the technical problems in his earlier analysis. Furthermore, he was challenged by Szreter (1988) on the basis that he failed to recognize the importance of the role played by public health campaigns and changing personal hygiene in the mortality decline in Britain.

Caldwell (1993) says that although Szreter once again drew attention to public health activities, especially at the level of local government, he did not discuss broader social and behavioural change.

Caldwell (ibid) maintains that there are additional factors besides medical and public health interventions on the one hand and per capita income on the other, that determine health and risk of death. Evidence for this has come largely from comparative studies of the contemporary Third World. A study by Caldwell (ibid) identified eleven countries with health achievements far beyond what would be predicted by per capita income. This study showed the strongest correlation with health success was the educational levels of women of maternal age.

As can be observed from the above discussion, the processes determining health status are complex and long term (Barker 1996). It is important to bear in mind the element of time when examining the factors that impact on health status. Wilkinson, (1996) points out that in effect, diminishing health returns to income at any point in time are accompanied by increasing returns over time.

Murray and Chen, (1993) suggest that multiple factors may determine the relationship between income and longevity, including the effectiveness of public policies and of expenditure on health.

Another theory on the determinants of health status is from Wilkinson, (1996) who asserts that: "Among the developed countries, it is not the richest societies that have the best health, but those that have the smallest income differences."

1.2.1 CHANGING VIEWS ON DEVELOPMENT

Barker, (1996) has traced a brief history of changing theories of economic growth versus equity for development. In the 1960s development was seen as virtually synonymous with growth and growth promoting policies were the order of the day. While economic growth would not initially reduce poverty, the income of the poorest would rise over time. This process is termed the 'trickle-down effect'. During this process inequality may increase further.

By the 1970s it was clear that little, if any, such trickling was happening and in mid-1970 a basic needs approach was developed with a focus on production at all levels of society. Investment in the health and the education of the poor was promoted.

Once again in the 1980s, policies were aimed at the highest possible growth rates, with growth taking preference over equity. From 1980-83 there was a recession, which resulted in an intolerable debt burden among the poor nations. By the mid-80s it became apparent that the adjustment policies that were part of the servicing of the developing nation's debt, were causing them too much hardship. By the 1990s there were renewed calls for equity to be re-established as a development goal. The WHO's Health for All, through primary health care by the year 2000, envisaged an equity-orientated health strategy (Alma Ata 1978).

The World Bank has rapidly emerged as a dominant force in the health policy arena, advocating investment in the health of the poor as a means of development (Zwi and Mills 1995). In recent years growth with equity has been espoused by agencies such as the World Bank (Barker 1996). Equity has become a vital constituent of economic development and an important aspect of health policy for health research priority setting.

1.2.2 EQUITY

The terms "equitable development" and "equity" are bandied about in the context of resource allocation. It is important to have a sense as to what they mean.

The allocation of health resources involves a concept of justice. "Health resources are allocated according to various mechanisms or criteria such as productivity or other ethical principles such as the principle of justice put forward by John Rawls in 1971 in 'A Theory of Social Justice.' Using Rawl's principles of justice, society should maximize the expected welfare level of the worst-off person in society. Thus when conflicting interests occur, effective health care would be distributed to those who are worst off" (Patrick and Erickson 1993).

There is ample evidence from the established market economies that a more egalitarian polity is associated with better health standards (Wilkinson 1996). Caldwell, (1993) demonstrated that a relatively egalitarian political culture is a precondition for superior health achievement by low income countries (Legge 1993).

In most parts of the world, equity is accepted as an important social and economic goal for the health-care system. The concept of equity means different things to different people. For example, equity can refer to resource allocation and distribution. One can also examine equity in terms of outcome, such as health status (Lalloo 1995).

Price, (1998 P 712) defines equality as being “concerned primarily with treating people equally with respect to some characteristic in which they are alike” and equity is “concerned more with finding some principle of fairness that could be applied to all people consistently.” Equality in health care could be defined as the equal provision of health care regardless of need and equity as the provision of health care with respect to need (Lowenson 1991) (Read health-care or health research). “Equity refers to fairness and justice. It calls for the recognition of differential need, such as those of disadvantaged population groups in addition to equality of rights” (Bryant *et al.* 1997).

Inequity refers to differences in health that are not only unnecessary and avoidable but also considered unfair and unjust (Whitehead 1990). Equity in health can be defined as equal expenditure per capita, equal expenditure for equal need, equal access for equal need, equal utilisation for equal need or even equal health status (Mooney and Drummond 1982).

Equity can be built into health research priority assessment through the ENHR initiative.

Economic efficiency does not include any principle of equity in health resource allocation. An economically effective allocation of resources means that no one in the community can

be made better off without making someone else worse off (Patrick and Erickson 1993). In order to achieve social justice in the sense of seeking health for all, it will be necessary

to divert considerable resources to the most disadvantaged in society. However, the DALY and similar measures which target the use of resources to maximize the benefits gained, is likely to help those who can most benefit, over and above those who are in greatest need (Barker *et al.* 1996).

In addition, it will be vital that equity be achieved in many other sectors that impact on health such as housing, income, education and the supply of water and sanitation.

“Each society must achieve a sufficient level of consensus about what equity means for that society to take effective action to reduce inequalities” (Essential National Health Research and Priority Setting 1997). The 1990 Report of COHRED, Health Research: Essential link to Equity in Development, concluded that research “will strengthen the ability - and the resolve - of developing countries to meet the needs of the most disadvantaged and, reinforced by international scientific and financial aid accelerate progress towards the fundamental goal of equity in health” (quoted in Essential National Health Research and Priority Setting 1997). Accordingly, the question of equity is of vital importance when setting research priorities in South Africa.

1.2.3 HEALTH AND DEVELOPMENT IN SOUTH AFRICA

The mortality profile in South Africa shows a combination of First and Third World diseases (Bradshaw *et al.* 1984). These include poverty-related diseases, as well as chronic diseases related to an industrialised lifestyle and the effects of trauma and violence. The latter relates to the social and political transition that is underway in South Africa. Demographic differences between race groups and the uneven development of geographical areas in South Africa reflect the socio-economic disparities arising from the apartheid policies of the recent past.

As discussed earlier, Cooper *et al.* (1998) have shown that some developmental policies can be detrimental to the health of sectors of the population. These would include land distribution and population resettlement policies which formed part of the separate development programme and, as such, are particularly relevant in the South African context. Cognisance must be taken of them in order to determine which health problems are to be addressed first.

It is important that health be incorporated into a country's developmental policies. The Reconstruction and Development Program (RDP) was initially promoted as the development initiative of the post-apartheid government (The RDP 1994). Although health was included in the RDP, there was little detail concerning health research. However, within two years, the separate ministry set up to implement the RDP was disbanded. RDP principles were still entrenched in the form of policy documents and legislation. In mid-1996, the government presented its new Growth and Redistribution Programme (GEAR). This signalled a significant shift in the African National Congress (ANC) policies towards development, with economic growth being the primary thrust. Social development, which includes health, clearly takes a secondary position within GEAR. Although redistribution still features prominently in GEAR strategy, it seems likely that the macro-economic adjustments with the reduction of the budget deficit and the curbing of state expenditure may seriously affect many of the RDP projects (Van Rensburg 1997). There is general agreement that GEAR will impose additional hardships on the poor rather than alleviating the inequities inherited from apartheid (Van Rensburg 1997). The National Progressive Primary Health Care Network, (NPPHCN), states that, "the premise that economic growth is an obligatory precursor to development is false;" instead, "when equitable development is pursued with vigour, economic growth will occur as a consequence" (Macro-economic policy and its impact on health development, employment, redistribution and crime. P 1).

1.2.4 POVERTY AND INEQUALITY IN SOUTH AFRICA

The Gini-coefficient is a measure of income inequality. It ranges from 0-1, with 0 representing absolute equality and 1 representing absolute inequality. The Gini-coefficient for South Africa is currently 0,58 the second highest in the world. "While economic growth contributes to poverty reduction, it may not necessarily reduce inequality" (Poverty and Inequality In South Africa 1998).

Achieving a reduction in poverty and equality with social and distributive justice is a fundamental challenge in South Africa without which, international experience suggests, the human development, economic and employment goals of the government may be hindered (Poverty and Inequality In South Africa 1998).

The South African government is committed to poverty reduction and a more egalitarian distribution of income and wealth. Since 1994 the government has been committed to prioritise the health needs of vulnerable groups such as the rural, peri-urban and urban poor, and women and children.

1.2.5 A MODEL OF HEALTH CHANGE

Decision support through models is widespread in many areas including the health sector. A model represents only a simplistic representation of a complex system. However, it provides a basis for recognizing interactions and processes (Lerer 1996 personal communication). A systematic approach to interactions between parts of a complex cluster is vital for successful strategy development (Porter 1993 - quoted in Lerer 1997).

Current epidemiological complexity requires more formal analyses of health priorities than ever before. In this context, the most viable scenario is the development of health systems that are pro-active, that anticipate problems and do not just react to crises (WDR 1993). Factors such as income, education, employment status and occupation universally shape the age and sex patterns of populations through their impact on fertility and mortality. In populations undergoing demographic transition, there is generally a decline in mortality followed by a drop in fertility resulting from improved socio-economic conditions. As fertility declines the population ages. The population age structure and corresponding cause of death patterns during the demographic transition are largely a function of the decline in fertility. In addition, with industrialization and urbanization a decline occurs mainly in the mortality of infectious diseases among the younger age groups. There is a consequent shift in the cause of death profile to chronic diseases and this forms part of what is called the epidemiological transition.

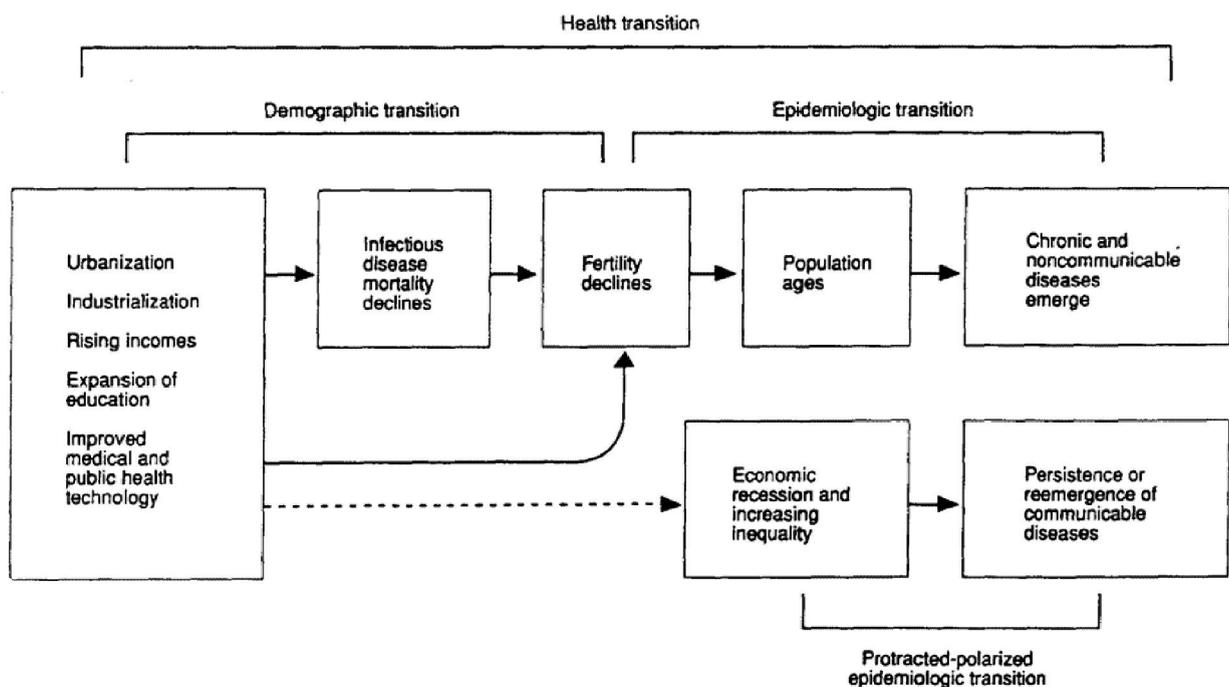
The epidemiological transition has been broadly described as referring to the complex long-term changes, (over decades or even centuries), in the patterns of health and disease as communities transform their social, economic and demographic structures. Omran, (1971) initiated the theory of epidemiological transition. He posited a set sequence of events starting with a preponderance of infectious diseases, followed by an era when chronic and degenerative ailments predominated.

On the basis of observations from some large middle-income populations Frenk *et al.* (1989) proposed modifications to Omran's theory with the protracted-polarised model of epidemiological transition. This model is characterized by the coexistence of infectious and non-communicable diseases in the same population persisting for a long time. In the protracted model more affluent sections of the population would have completed the transition, while economically disadvantaged groups continue to suffer from pre-transitional pathologies. This bi-polar model applies to South Africa.

Prioritisation in health research must be viewed within the context of the health transition. The epidemiological transition together with the demographic transition have become known as the health transition (Bradshaw *et al.* 1995). The health transition refers to changes in fertility, mortality, cause of death composition, disability and the health system's response to these trends (Murray 1996 and Frenk 1989).

Figure 1 is a model of health change from Mosley *et al.* (1993). The first section in the figure refers to the determinants of health status - the driving forces behind health. The protracted-polarised epidemiologic transition describes the current South African scenario of health change.

Figure 1: Relationships among the Demographic, Epidemiologic and Health Transition



Source: Mosley WH *et al.* (1993)

The model is useful for the analysis of health status in developing countries but the historical context, such as colonialism, needs to be taken into consideration as well. For example, in Africa there has been urbanisation without industrialisation which is not shown in the model (TIME 1994). The health transition occurred in industrialised countries after there had been substantial economic improvements.

According to Frenk: “Perhaps the major challenge is to make the health-care transition respond to the epidemiological transition in a way that reduces the inequities brought about by the protracted-polarised model” (draft Frenk circa 1995).

Transition theory as it stands, does not explain how social and economic changes are related to health transformation (Bradshaw *et al.* 1995). Murray and Chen, (1993) have proposed that three established theories of mortality change, viz the income and food theory, the dissemination of modern technologies and socio-cultural change that includes changing beliefs and health behaviour, explain some aspects of the worldwide phenomena of long term general mortality decline in an interactive way.

South Africa may not be in an economic recession and while there has been some redistribution of wealth, there is evidence that inequality is not being reduced but is being structured differently (Sunday Times 1999).

A feature of the protracted-polarised model is the juxtaposition of a developed and an underdeveloped sector, that comprise the health arena. One cannot ignore the developed sector when setting priorities. This is of particular relevance to South Africa where one would want to at least maintain some areas of excellence in the developed sector and promote some specific research areas to the level of internationally competitiveness.

In developed countries the demand for health care is growing. Bobadilla (1996) refers to the ‘health utilisation paradox’. As income per capita rises, the utilisation of health care services and the unit cost of treating an individual also increases.

This can be explained by four socio-economic changes, which correlate strongly with income:

1. An aging population consumes more services and more costly services (Mosley *et al.* 1993).
2. As people increase their income, then tobacco consumption, alcohol abuse, lack of exercise and excess animal fat consumption becomes more prevalent. This stage of regressive behaviour places a heavy burden on health services (Bobadilla and Costello 1996).
3. More education and information lead to greater health care demand (Berman and Ormond 1988).
4. New drugs and techniques in clinical medicine lead to higher costs of health-care with marginal benefits to population health status (Bronzino *et al.* 1990).

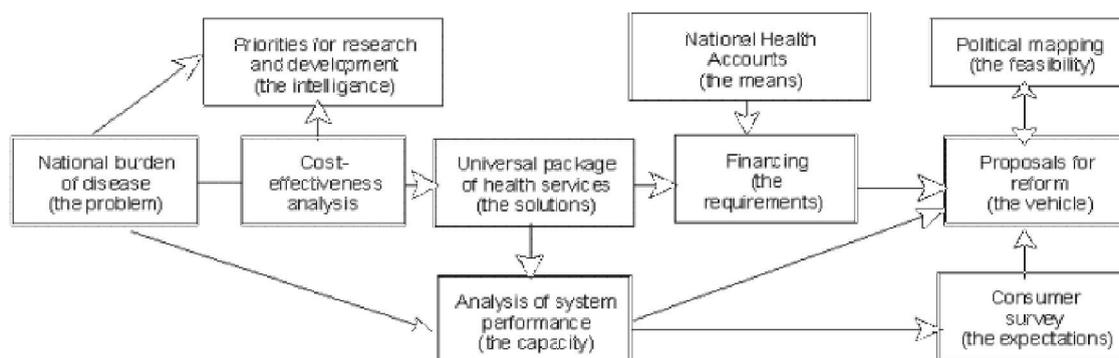
The above scenario applies in part to South Africa and serves to further complicate the priority-setting process for research.

1.3 HEALTH RESEARCH AND HEALTH SYSTEM REFORM

Many countries have health systems that are in crisis with escalating costs and as a result, health system reform ranks high on many political agendas. At the start of the new millennium virtually every country whether industrialized or less developed, is engaged in a process of health system reform (Zwi and Mills 1995).

Recent analyses of health sector reform provide useful conceptual maps of the health system and health policy (Frenk 1993 and 1995; Walt 1994). Frenk (1995 P 258) states that “if health systems are to keep up with the wave of innovation that has swept through economics, politics, culture and technology, they must be renewed.”

FIGURE 2: Model of health system reform



Source: Frenk (1995)

Fortunately, there are a number of analytical tools that can be used by the policy community to increase the quality of their decision-making. According to Frenk (ibid), one of the current challenges is to integrate these different approaches into a coherent framework for policy analysis. Figure 2 shows the approach used to develop and apply such a framework for a study in Mexico from 1993 - 1994. This is a clear, comprehensive model which, with some modifications, could be applied to South Africa. From the model it can be seen that health research prioritisation is an integral part of the process of health system reform. In Figure 2, priorities for research and development are depicted as 'the intelligence' arm of the system. (The national burden of disease, 'the problem' together with cost effectiveness analysis are tools that help determine research and development priorities).

According to Barker (1996), the conceptualisation of a system clarifies a particular area for further analysis. Barker states that thinking through the environment in which the system operates refines the model further. Once one system has been modelled, the systems that represent its component parts can in turn be modelled, taking the analysis of actions and interventions to a more detailed level.

Priority setting for health research cannot be examined in isolation as it is part of the broader health system. The health system is in turn affected by the broader social context within which it operates.

A detailed model for health research prioritisation in South Africa needs to be developed. This model should be part of a more general health systems model. It should incorporate all stakeholders relevant to the research prioritisation process, the different levels at which interactions occur as well as the environment in which the system operates. This should facilitate transparency for policy decisions for research prioritisation. Terms used in the model should be clearly defined as part of consensus-building and all terms of reference should be clearly stated. As part of the initial stages of determining health research priorities it will be necessary to examine how health research will be classified. The model should include the means of channelling funds and controlling budgets and research evaluation procedures.

1.3.1 ESSENTIAL NATIONAL HEALTH RESEARCH

Frenk wrote that a research agenda must be an integral part of every initiative to reform and renew health systems. He added that, “What is essential about ENHR is its commitment to goals like equity, quality and efficiency, which are precisely the same ones that the reform movement promotes” (Essential National Health Research and Priority Setting 1997 P 3, from Research into Action 1997).

ENHR represents an integrated strategy for organising and managing health research to promote health and development based on equity and social justice. The essence of ENHR is a dynamic partnership between policy makers and service-providers, researchers and the community. Setting priorities is identified as one of seven elements of ENHR which also includes ENHR promotion, a national ENHR mechanism, strengthening research capacity, networking, funding and evaluation of ENHR (ENHR 1991[b]). The Council on Health Research for Development, (COHRED) is an international non-governmental organisation, (NGO) that aims to support, broaden and strengthen the linkages and competencies of various stakeholders in the country and at international levels (Essential National Health Research and Priority Setting 1997). The primary goal of global priority setting is to help countries with the greatest health needs and fewest resources; i.e. international health

priorities should reflect national priorities. (Essential National Health Research and Priority Setting 1997 1990). This goal is as relevant now as it was a decade ago.

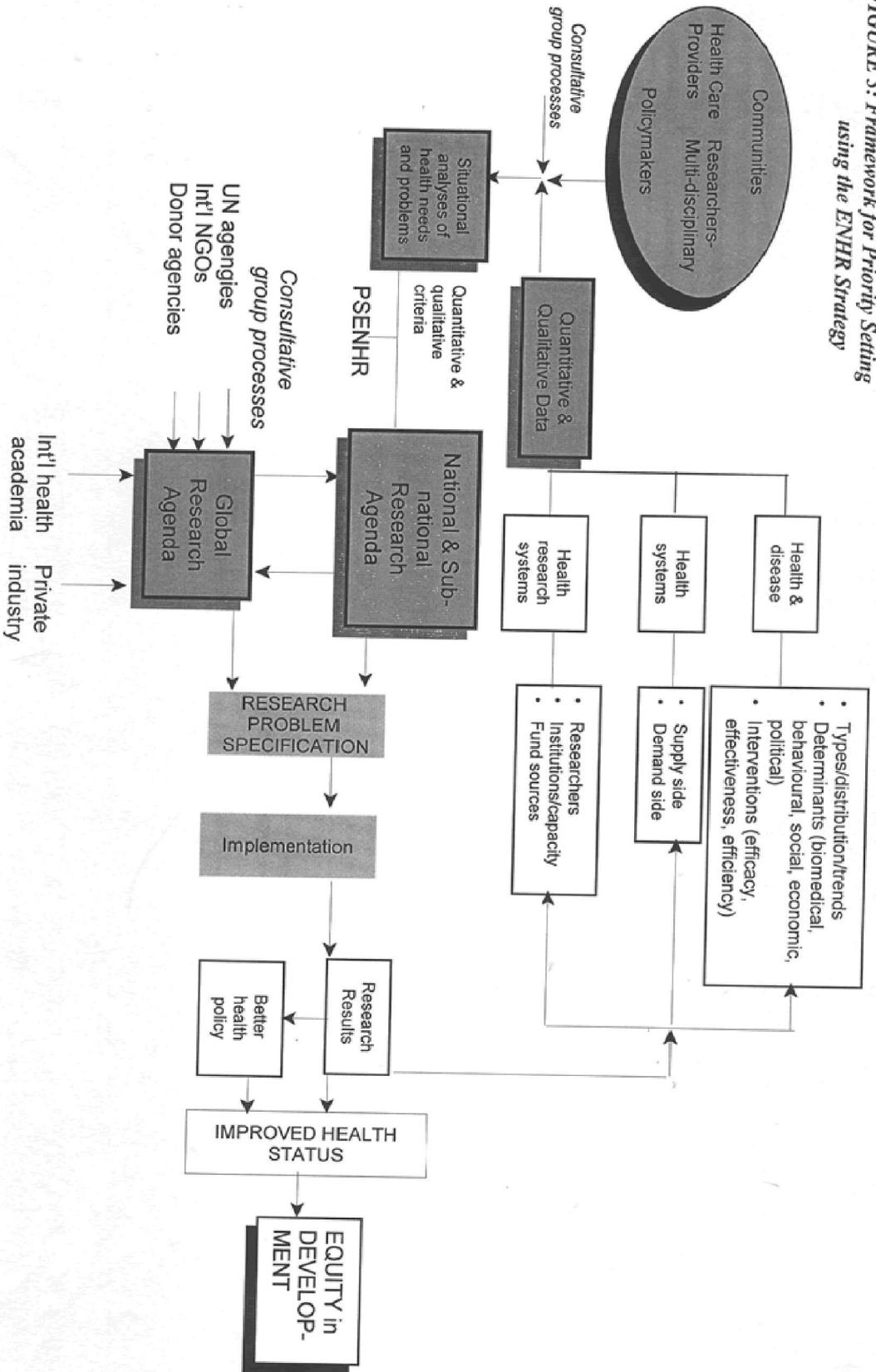
Setting priorities has been acknowledged as an important element of ENHR but only guiding principles on general procedures have been provided. A recent review of experiences from several countries has provided practical suggestions on how to proceed with such an exercise (Essential National Health Research and Priority Setting 1997). Bland, (Research in Action 1997) in particular, warns that if ENHR is to address the 'felt needs' of communities, it is important to consult and involve them in the process of setting priorities.

A useful framework for priority using the ENHR strategy is shown in Figure 3 (Essential National Health Research and Priority Setting 1997). The framework reflects 'demand-side' thinking " focussing on health needs, peoples' expectations and societal trends in contrast to supply-side thinking alone, with its focus on new knowledge or new technology" (Essential National Health Research and Priority Setting 1997 P 4).

Where ENHR strategy is used, the different stakeholders in research are involved in consultative group processes utilising qualitative and quantitative data, in order to determine health needs, problems and priority research.

The framework depicted in Figure 3 also includes the links between the national and global research agendas. However, a section for the evaluation of the research is lacking and can be built into the current model. The framework should represent a systematic, flexible, comprehensive process for setting, implementing and evaluating health research priorities in South Africa.

FIGURE 3: Framework for Priority Setting using the ENHR Strategy



Source: COHRED (1997)

1.4 PRIORITISATION

No matter how desirable health research is to society, there is always the problem of scarce resources and competing uses for available resources. In general the scarcity of resources means that not everybody's needs can be met. There is a need to decide what should be dealt with first. This need to prioritise and so allocate resources optimally is particularly relevant in developing countries where there are relatively less resources and more basic needs.

In general, planning can be considered a rational response to scarcity and priority setting an integral part of planning. Unfortunately there is limited literature about the theory of prioritising health research. In the health arena it has been recognised that priority setting is often not given sufficient attention (Green 1992). Furthermore, as Mooney *et al.* (1997) have asserted, the important issue is not whether to prioritise, but *how* to prioritise. This assertion is made in the context of health care prioritisation and it applies equally well to health research prioritisation. Prioritisation is an expensive process in terms of time and money and is ongoing. The setting of priorities for health research emerged as a pivotal issue for analysis.

The health priorities of a country and the health research priorities are linked and overlap to some extent. However, they are not one and the same and therefore it will be necessary to explore this relationship.

1.5 OBJECTIVES AND METHODS

The overall aim of this thesis is to examine prioritisation for health research with specific reference to South Africa. The specific objectives and sub-objectives are enumerated below. Although there will not be a systematic policy analysis for health research prioritisation in South Africa, it is however an important underlying issue that is referred to throughout the study.

1.5.1 OBJECTIVES

1. To describe the technical approaches used for prioritisation in health research and examine the classification of health research. The development of a systematic process and the identification of appropriate techniques for prioritisation for health

research is explored. In addition, in order to include the international health research prioritisation experience, there is an examination of an initiative which reviewed global research priorities for developing countries.

2. To examine how burden of disease quantification fits into the process of setting priorities. To explore the role of the DALY and other composite measures of health outcomes in priority setting for health research. To investigate the extent to which additional information is contributed through composite measures and assess the impact on priorities. Specifically, to examine the extent that disability/morbidity data contribute to an assessment of the burden of disease.
3. To provide a thorough critique of the DALY by analysing the technical and conceptual criticisms levelled at the DALY.
4. To describe the process of setting research priorities that has occurred in South Africa. In particular, the use of ENHR to manage health research on a national basis is examined in the South African context as well as an investigation of the extent to which explicit prioritisation processes have been used.
5. To develop a model for setting priorities through specific recommendations that are distilled from the various sections of the thesis. It is envisaged that this model incorporates an ENHR strategy and burden of disease methodology. This tentative model will serve to guide and improve the health research priority setting process in South Africa. To ensure that the various issues that are discussed become an integral part of the overall framework for prioritisation. To suggest directions for future research.

1.5.2 METHODS

The methods employed to examine the setting of health research priorities and apply them in South Africa range from extensive literature review to statistical analysis of data published from the GBD estimates. This variety of seemingly disparate methods, each make a unique contribution to assist in achieving a more complete analysis and

understanding of this complex subject. An analytic framework to examine prioritisation in health research was developed drawing on multiple disciplines, which included health policy analysis, epidemiology, public health, economics and statistics.

1.5.2.1 Method for objective 1: Approaches to setting priorities

An extensive literature review will be undertaken in order to examine the various classifications of health research and develop a framework for the approaches to setting research priorities. The literature review comprised a MEDLINE search, with subsequent follow-up of literature from the references of selected articles. In addition use was made of some relevant grey literature.

1.5.2.2 Method for objective 2: Health outcome measures

An epidemiological approach is employed giving a brief outline of the historical development of health outcome measures. These measures are compared in terms of utility for helping to determine priorities in the health arena.

A statistical approach is used to assess the contribution of the constituent parts of the DALY. Premature mortality and disability will be analysed in terms of age, sex and disease group, specifically for Sub-Saharan Africa. The results of regression analysis using Years of Life Lost (YLLs) and Years Lived with Disability (YLDs) with mortality will be analysed to ascertain the contribution of composite measures for priority setting.

Similarly, Life Expectancy versus the summary health measure, the Disability Adjusted Life Expectancy (DALE) calculated for all the WHO member, states will also be analysed. These analyses will investigate whether the disability component is important for determining population health status, the performance of health systems and ultimately health research priorities.

1.5.2.3 Method for objective 3: DALY critique

A detailed review of the critique of the DALY will serve to examine the burden of disease methodology including the way inherent assumptions affect the determination of priorities in health research.

The review method employed, is to group the criticisms gleaned from the relevant literature into technical and conceptual issues and to analyse what effect these issues have on priority setting. Suggestions to rectify the shortcomings of the DALY are made specifically for those criticisms that are of relevance for prioritisation.

Particular attention is given to equity and women's health.

1.5.2.4 Method for objective 4: ENHR in SA

Committee reports, green papers and other documents from grey literature will be reviewed to describe how health research priorities have been determined and funded in South Africa. As South Africa is undergoing social and political transformation after the demise of apartheid, a historical and a current perspective will be necessary to aid the understanding of the development of an indigenous process of setting health research goals.

This section will include a brief history of ENHR in South Africa and a fairly detailed analysis in terms of the process for setting priorities for health research that emerged from the first priority setting Congress held in South Africa in 1996.

1.5.2.5 Method for objective 5: Synthesis of an operational framework for health research prioritisation in SA.

The basis of the tentative prioritisation model should integrate the following: The analytical framework for identifying health research to address health challenges. A suitable classification system of health research. The appropriate selection of health or burden measures. The ENHR strategy that is to be developed and implemented in South Africa should be included in the model.

Additional recommendations for the suggested framework will include those arising from discussion of the components critical to the prioritisation process.

1.6 CHAPTER OUTLINES

Chapter one introduces health research priority setting in the context of improving health and social justice. It provides the motivation for the choice of this particular topic and the specific objectives and methods used. The introduction includes an historical perspective on health and development and a working definition of health research. The sections that provided the necessary background for the thesis included a brief discussion of health research and the distorted global health research agenda. In addition, the role of health policy and health policy analysis for priority setting was touched on briefly. Following this was an exploration of the relationship between health and development, as well as the important issue of equity in the context of priority setting. There is also a perfunctory look at models of health change and health reform and the respective contributions made to understanding health systems of which research is an integral part. This chapter serves to integrate the general background information on health and development into the South African context. This includes an historical background of health research priority setting and some discussion on health research expenditure in South Africa. The discussion on health system reform applies particularly to South Africa, where re-prioritisation is an integral part of health system reform. The Essential National Health Research (ENHR) strategy is introduced and a blueprint for a framework for setting health research priorities incorporating ENHR in South Africa is presented. The role of research as a catalyst for change and the necessity that research anticipate and provide solutions for future health problems of mankind was highlighted. Setting priorities for health research, especially resource poor settings, is shown to be a most important issue, requiring further analysis.

In chapter two, a model is presented that brings together various factors that need to be considered for appropriate intervention decisions, which includes health research, for improving health. This is conceptualised at a global level. The chapter comprises a detailed exploration of the approaches to setting health research priorities by examining the literature. It is observed that health research prioritisation can be viewed from different perspectives. The setting of priorities is determined by applying an analytical framework, classifying the research into specific types as well as incorporating the various criteria that are used to rank research needs.

The analysis of the global health problems in order to identify priority research needs by the WHO Ad Hoc Committee on Health Research WHO is used as a model in South Africa with some adjustments. This model utilises a sequence of specific steps as part of the priority setting process with separate exercises for the different approaches.

Since the burden of disease is a key element of the health problem approach for setting priorities, it is important to examine the measurement of health outcomes. Chapter three commences by looking at the determinants of health status and defining different concepts of health. Thereafter the development of various measures of health outcomes are discussed. This discussion includes an historical perspective, the underlying theory as well as the appropriate use of these measures of health outcome. There is a detailed account of the DALY (Disability Adjusted Life Year) focussing on its advantages when compared to other similar measures. It is an important measure used by the Ad Hoc Committee on Health Research. It is the basic unit of measurement used to identify a health gap and is a composite measure of mortality and the disability associated with morbidity or injury.

Besides the DALY, another important summary measure of health status is the DALE (Disability Adjusted Life Expectancy). Both the DALY and the DALE have a morbidity component. With the DALY the measure, mortality is augmented by years of life lost to disability and with the DALE, life expectancy is adjusted for disability. The question arises as to what the morbidity component adds to the measures. This is analysed using the statistical tool of regression analysis.

From the discussion on the development of composite measures, it can be ascertained that whilst some are appropriate for measuring health status, others measure the burden or health gap. Mortality may well be sufficient as a measure of health status. However, it does not adequately capture the measure of health burden on its own.

The champions of the DALY state that the DALY has the potential to describe the health status of the population i.e. the quantity of ill-health and the burden of disease, set health research priorities and assist with the allocation of resources as well as contributing to the evaluation of interventions and programmes for improving health. In chapter four, these assertions are appraised with the emphasis on the DALY as a measure for allocating

resources and more specifically for setting health research priorities. During the last few years there has been extensive debate over technical and conceptual issues concerning the DALY. The main criticisms concern the assumptions and underlying values in terms of the application of the DALY.

In the next section of chapter four, the focus moves from the setting of priorities for health research to the issue of who sets priorities for whom. This concerns the DALY and resource allocation. In this context, the issue of equity is addressed briefly. In particular, the gender and poverty implications of the DALY are appraised. This was done by means of an applied critique of the DALY and women's health. Although gender concerns both men and women, women's health priorities are highlighted as gender differences are especially significant for women as they result in inequality and discrimination.

In a separate analysis, it was demonstrated that the burden of disease based on DALYs does not differentiate the needs of the poor. The increasing health disparities between rich and poor countries and the feminisation of poverty cannot be ignored. The DALY can be used to help mitigate inequality in health through, for example, stratifying data and utilising data that highlights inequality in health. In order to use the DALY effectively for resource allocation, it has to be used in conjunction with CEA and include the assessment of avoidability. Chapter four concluded that the DALY is a most useful adjunct tool for setting country-specific health research priorities.

Chapter five describes the South African process of health research prioritisation and reflects on the recent experiences in South Africa so that priority setting can be improved and also contribute to the numerous research prioritisation initiatives undertaken in other countries. In particular, ENHR has been identified as a necessary strategy to manage health research on a national basis so as to meet the needs of the country. Recommendations are made as to how South Africa can develop an indigenous model for prioritising and enhance the implementation of ENHR.

ENHR in South Africa is to be implemented against the background of recent development initiatives which impact on the health arena as well as the current patterns of health

research expenditure. The general procedures and the results of the first ENHR priority setting Congress in South Africa are presented and discussed.

In addition, there was discussion on the health research priority setting of the Foresight project, the MRC and the Health Systems Trust.

AIDS is emerging as a huge global health problem. As such it serves as an example of the current process of research prioritisation in South Africa.

The concluding chapter is a synthesis of the preceding chapters. This is achieved by highlighting the important recommendations to aid the development of a systematic process of setting health research priorities in South Africa. The future directions for health research prioritisation are also pinpointed.

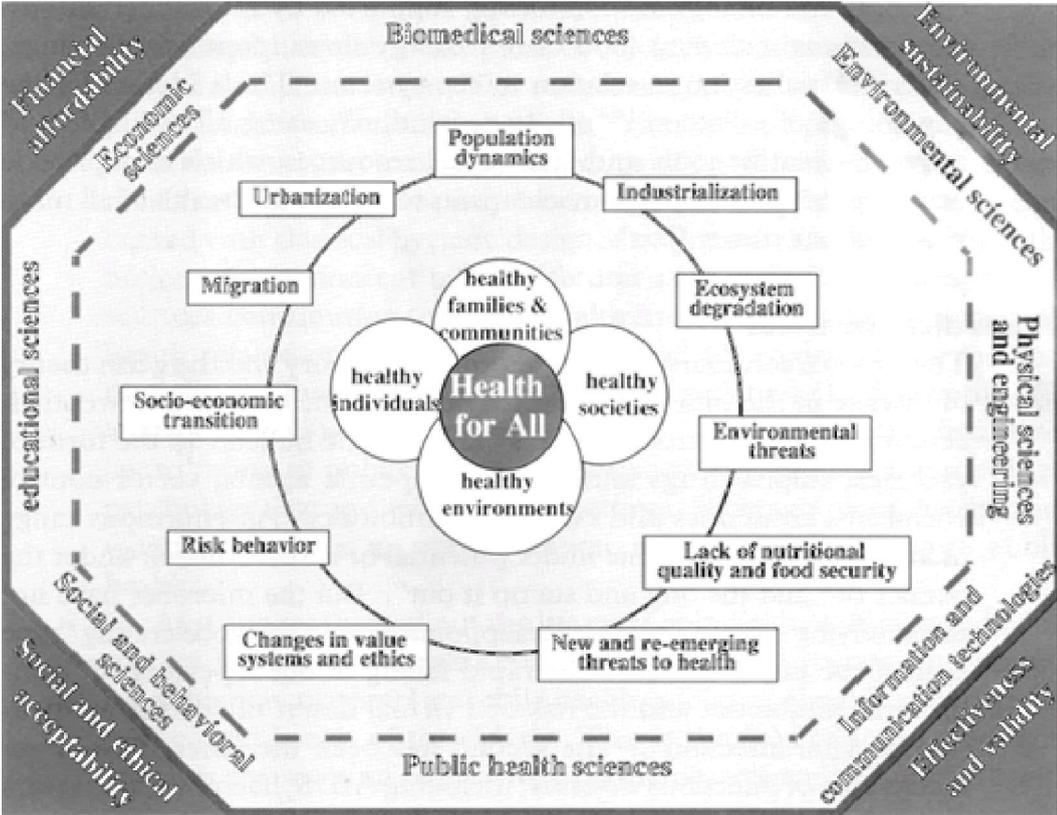
CHAPTER 2

THE APPROACHES TO SETTING HEALTH RESEARCH PRIORITIES

2.1 SETTING HEALTH RESEARCH PRIORITIES

Since priority setting does not occur in a vacuum, it is necessary to see it in the context of the health system, the myriad of factors that impact on health and development, the sources of knowledge available to address health problems and the constraining values. A WHO report on a health policy agenda to support global health development provides a diagram (Figure 4) that captures the inter-relationship between values, disciplines and the various determinants of health and incorporates the levels of health analysis with these determinants and how they impact on the central issue of ‘Health for All’. All these factors interact to guide the choice of appropriate intervention decisions on health problems.

FIGURE 4: The factors that impact on health and guide the choice of appropriate intervention decisions on evolving health problems



Source: A research policy agenda for science and technology to support global health development - A synopsis. WHO 1997

All scientific disciplines shown in the octagon in Figure 4 contribute to increasing the knowledge base. Decisions on action concerning health problems which includes research priority setting based on multi-disciplinary information are tempered by values of social and ethical acceptability, effectiveness and validity, environmental sustainability and affordability.

Figure 4 is a fairly comprehensive diagram and is useful as an explanatory device. However, it does not provide insight to the setting of health research priorities, or an appraisal of systems of prioritisation. According to Walt, (1994) health policy is about process and power. It is concerned with who influences whom in policy making and how this happens. In contrast, policy is about content for many people and although they agree "that politics cannot be separated from policy there is little explicit discussion in the literature about political systems, power and influence and people's participation in policy making" (Walt 1994 P 1).

In terms of the prioritisation of health research, main stream literature suggests a technocratic approach to priority setting with burden of disease data, cost effectiveness analysis and essential packages. Little attention is given to other dimensions of priority setting such as the political context, the decision making process, the institutional and management implications of proposed priorities, the ethical implications of various methods and the role of social values in the allocation of health resources (Bobadilla 1996).

Walt and Gilson (1994) have argued that with the focus on the technical aspects of policy content and the neglect of the process of policy development and implementation, this has resulted in the expected outcomes of policy not being realized or policy changes not being effectively implemented.

Walt, (1996 P 227) describes "a simple framework for policy analysis which takes account of contextual factors, processes of policy-making and the influence of actors as well as substantive content." The 'content', 'context' and 'process' can be conceptualized

as the corners of an equilateral triangle, with actors, both as individuals and as members of groups within the triangle.

An examination of the process of health research priority setting involves analyses on how decisions concerning these priorities are arrived at, as well as who and what influences the decision-making process. While all the elements are extremely important the focus will be restricted to the decision-making dimension of prioritisation rather than the whole process of prioritisation.

2.1.1 METHODS FOR SETTING PRIORITIES

Ronayne (1984) identified two extreme methods for setting research priorities, i.e. the rational and the incremental.

1. The rational method involves collecting all available information on what is needed and what is possible, identifying objectives and collecting data on what value is placed on these objectives by various groups.
2. The incremental approach involves inching forward from what is happening now. The degree of movement at any time being determined by the political context, which includes not only ideology but also the different interest groups in society (Green 1992).

Internationally, shifts towards a rational approach are becoming evident with the development of a range of tools to assist policy-makers in improving the policy process in general as well as setting priorities. However, Foltz (1996) reflected on the lack of impact of the technocratic planning tools developed for management in the 1960s and 1970s and argued that prioritisation cannot be resolved by purely technical and scientific means as it is a political process that involves an underlying value system.

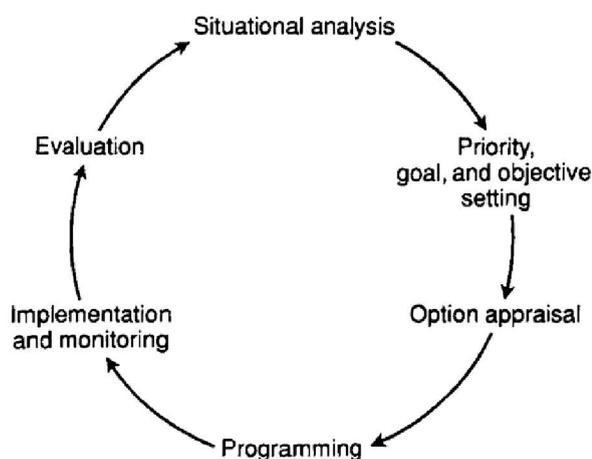
According to Foltz (ibid), the rationalist approach is particularly well represented in the health sector and is employed to set priorities. This may reflect the influence of epidemiologists and economists in health planning at the expense of the more pragmatically orientated social sciences such as political science and sociology.

The incrementalist approach has until recently prevailed in South Africa, Parry *et al.* (1992) have argued that the incremental approach is unsatisfactory as it discourages innovation and action, priorities can be self-perpetuating and often do not meet public needs. They suggested that although the technocratic or rational approach is limited by the nature and quality of health information available and by the judgements made about such information, it would be preferable to use this approach.

Nevertheless, the incrementalist view of the policy process has gained considerable currency as it aptly describes what decision-makers actually do, i.e. they engage in “an interactive process of mutual adjustment” (Foltz 1996 P 211).

Green (1992) suggests realistic rational planning which combines technical skills with a recognition of the political process. Figure 5 is a diagrammatic representation of planning as a cyclical set of activities. Prioritisation is clearly placed in a continuous process of ongoing planning and evaluation.

FIGURE 5: Diagrammatic representation of planning



Source: Green (1992)

According to Green (1992 P 34), the formalities of planning is only part of the process and the “relationship between planners, policy-makers, service-managers and the communities in the planning process is critical to the success of planning.” These

political components are an integral part of the planning cycle. However they are not reflected in the diagrammatic representation of the planning cycle shown in Figure 5.

2.1.2 LEVELS OF PRIORITY SETTING

According to Ham, (1995[b]) priorities are set at a number of levels, ranging from the macro to the micro. Although Ham (ibid) refers specifically to different levels of priority setting for health care, the concept can be adapted for use in describing priority setting for health research. In the case of health research, these levels would reflect a combination of geographic levels and levels of health research organisation and are shown in Table 1.

Table 1: Different levels of health research priority setting

| | |
|----|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. | Global agenda (e.g. international agencies and multinationals) |
| 2. | National allocation of resources to institutions (e.g. health-care, research or academic) |
| 3. | Allocation to broad research programmes (e.g. AIDS, chronic diseases of lifestyle), targeted academic disciplines (e.g. health economics, paediatrics) or geographic levels (e.g. as province or district) |
| 4. | Allocation to research projects within programmes or academic disciplines |

Adapted from Ham (1995[b])

The first level is a global one which includes international agencies and multinationals. Level two is the national level and incorporates the Department of Health, teaching hospitals, universities and research institutions such as the Medical Research Council in South Africa. Level three defines research areas and level four refers to very specific research topics.

2.1.3 CLASSIFICATION OF HEALTH RESEARCH

For health research prioritisation it is useful to place health research into different categories according to the primary purpose of the research. As with any classification system there tends to be oversimplification. However, the classification of research types provides a framework for organising and planning health research. "Sometimes

careful specification of a research problem itself suggests the forms of research needed to address it” (Essential National Health Research and Priority Setting 1997 P 13).

Health research can be divided into basic and applied research which are carried out in the laboratory, clinical and community setting (ENHR 1991[a]). Basic or fundamental research refers to the creation of new knowledge and applied research refers to problem orientated research which leads to applications, i.e. defined as the application of existing knowledge. Applied research comprises both strategic and intervention research. Strategic research is the problem-solving component of research in which knowledge is generated about specific health needs and problems. Intervention research is focussed on the development and evaluation of interventions (Investing in Health and Development. Report of the Ad Hoc Committee 1996).

The purpose of basic or fundamental research is to increase knowledge about questions of scientific significance. The purpose of strategic research is to increase knowledge about a particular problem in order to reduce the impact of the problem with further development and evaluation. The relative contribution of the problem-solving and knowledge-gaining components vary with the particular research project (ibid). “Research efforts may be targeted for short, medium or long-term results. The longer term the research efforts, normally the higher the ratio of applied to basic research” (ACHR 1997 P 18). The serendipitous nature of basic research has often been referred to. However, curiosity driven or ‘blue sky’ research may well not result in important applications (ENHR 1991[a]).

Aside from categorising research on the basis of the purpose, it is possible to categorise research according to type. For instance, an adaptation of Frenk’s research types, includes biomedical, clinical, population and health systems/policy research (Barron *et al.* 1997).

In this framework research is divided into biomedical, clinical, epidemiological and health systems research. Biomedical research refers to health problems/conditions, biological processes and pathological mechanisms. Clinical research refers to the

efficacy of diagnostic, therapeutic and preventative procedures. Epidemiological or population research refers to the frequency, distribution and causes of disease.

Each of these broad research types can be linked to specific academic disciplines and methodologies. These groupings of scientific disciplines can facilitate resource allocation for research infrastructure and capacity building as well as the subsequent evaluation of health research but are not directly useful in the prioritisation process.

Barron *et al.* (1997) suggest that health systems research has two main components: health policy research and operational research. The latter refers to the delivery of health services, preferably at local level, for which there is a great need in South Africa (Barron *et al.* 1997). “Health policy research integrates the results of different types of research to select policy options” (ibid P 236). It also focuses on inter-sectoral issues, for example, the interaction of the health services with the environment (Barron *et al.* 1997).

The modified version of Frenk’s classification system can also be looked at in terms of the level of analysis. The biomedical and clinical research categories concern the individual or sub-individual level. The population or epidemiological and health systems research categories covers the population or health system level (Barron *et al.* 1997). An alternative way of grouping the biomedical and population research categories is to refer to health problems or conditions while the clinical and health systems research categories refer to the health-care responses.

2.1.4 ANALYTICAL FRAMEWORKS

Health research priorities can be examined from different perspectives. According to the literature, one approach is to rank the health research needs according to the priority of the health problem (Feachem *et al.* 1989). Alternatively, priorities in health research can be set by prioritising groups of people (ibid). A third means of prioritising in health research is to examine the potential health gain from different types of interventions that have broad effects such as improvements in water supply, sanitation, maternal education and food supplementation (Murray 1990). A fourth perspective is the health systems approach which ranks health systems issues according to the importance of

the problem. An example of this is health financing which would impact on the entire health system (Janovsky and Cassels 1996). Although four perspectives have been identified, it would appear that there are basically two distinct perspectives viz. a health problem or a health systems approach. Prioritising groups of people involves first targeting certain groups such as women and children or rural populations and thereafter setting priorities using either a health problem or systems approach. The broad intervention approach could be considered similar to the systems approach.

Feachem *et al.* (1989) defines a health problem resulting from a non-trivial cost or consequence of a state of ill-health. They provided a framework whereby a health problem can be separated into four types of research depending on the extent and nature of the knowledge needed to overcome the problem. These are shown in Table 2 and range from describing the magnitude of the problem to operational research examining the delivery of interventions. The determinants of a health problem include both biomedical and psycho-social components. Interventions can further be divided into: Health Promotion; Prevention of Disease, Treatment and Rehabilitation.

Another category for research, described by Feachem *et al.* (*ibid*) is health services research which is not derived from a particular health problem but from a concern about the overall financing, organisation and operation of the curative and preventative services. These five categories have overlapping boundaries. To some extent there is a natural sequence implied with one type of research leading onto the next a kind of hierarchy in terms of overcoming the problem (*ibid*). Combinations of different types of research are sometimes necessary to solve a particular research problem.

Janovsky and Cassels (1996) referred to *health policy and systems research* in a more comprehensive manner than the fifth category designated by Feachem *et al.* (1989). The former incorporates all aspects of a health system in terms of demand, supply and the mediating organisations. Table 2 summarises and combines Feachem *et al.* and Janovsky and Cassels' classification of health research.

Table 2: Types of health research

| Health problem approach: (Feachem <i>et al.</i> 1989) | Knowledge arena |
|-----------------------------------------------------------------|------------------------------------------------------------------------------------------|
| Health problem research | describes the magnitude of the problem |
| Aetiology research | focuses on pathological processes (biomedical and psycho social) |
| Intervention research | looks at the development of effective interventions |
| Operational research | examines the delivery system |
| Health systems approach: (Janovsky and Cassels 1996) | Knowledge arena |
| Demand side | includes individuals and households and populations |
| Mediating organisation | comprises the institutional purchasers and the state |
| Supply side | involves resource institutions, service providers and agencies in sectors outside health |

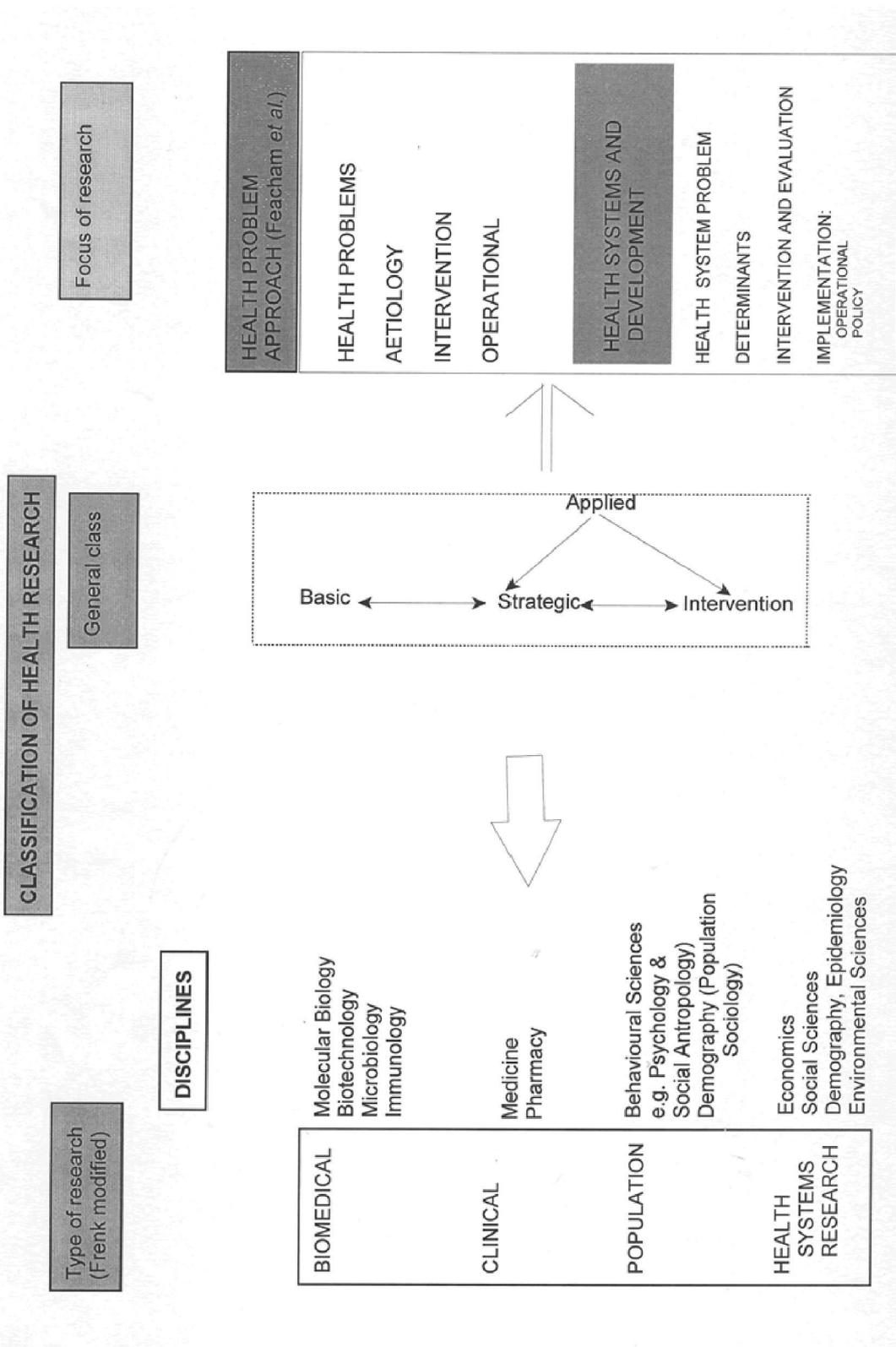
However, it is difficult to derive specific health system and policy research projects from Janovsky and Cassels' health system classification. Feacham *et al's* framework can also be applied to health systems and policy. The foci of research for health systems can be grouped into the following categories: Magnitude of the problem; Understanding the system factors; Development and evaluation of interventions and Implementation Research. Implementation Research can be divided into two groups namely, Operational and Policy Research.

2.1.5 FRAMEWORK FOR ANALYSIS AND CLASSIFICATION

Figure 6 attempts to show by means of a schematic diagram the above-mentioned research classifications with the analytical frameworks. (Figure 6 shows a section of Figure 3, Chapter 1 in more detail). There is correspondence between the type of research and the focus of research. This can clearly be seen by examining the scientific disciplines which link to the respective research classifications. These cross-linkages have not been depicted in Figure 6 as this would result in a confusing array of criss-crossing lines.

Figure 6 shows how the general classes, namely, basic and applied research, relate to the two health research analytical frameworks that are presented, namely, a health problem and a health system approach. These two approaches are concerned with the identification of specific health problems or health systems issues that need to be remedied, i.e., essentially applied research.

FIGURE 6: Framework for analysis and classification of health research



2.1.6 CRITERIA FOR RANKING

Different analytical frameworks will generate different lists of research priorities. The application of the framework of Feachem *et al.* or any other perspective, merely generates long lists of health research needs. Feacham *et al.* (1989) argued that prioritisation is essential and it is necessary to rank the list. Judgements in prioritisation involve a weighting of values. The technical methods used to assist decisions on priorities generally mask the underlying value judgements. Several values can be identified that can guide decision making. These usually include the following: effectiveness, efficiency, impact, equity, consumer satisfaction, capacity and sustainability. These can be broadly grouped as efficiency, equity and sustainability. Criteria provide the means whereby the health research needs can be ranked. The selected criteria become the expression of the weighting of the underlying values.

A health problem approach focuses on the magnitude of the health problem as the fundamental criterion. However, there are different ways to measure this which range from objective quantification of mortality and morbidity through to the perceptions of stakeholders such as the community. A health research priority is established precisely when there are no cost-effective solutions to a health problem (Frenk 1995). Hence, 'a gap in knowledge' that necessitates further research is a criterion in its own right.

An important criterion in the South African context is equity. Unless target groups such as marginalised or minority sectors of society are identified within a health problem approach, equity is generally neglected in this approach. When using a population focus for determining priorities in health research, the target group is generally selected through historical disadvantage. Equity is an underlying criterion in this approach. Janovsky and Cassels (1996) suggest that in the case of health systems research, there is a need to identify the importance of a topic. They recommend that if a topic cannot be judged in terms of impact on health status then it should be examined in relation to other policy objectives or values such as efficiency, equity in allocation, equity in outcome or consumer satisfaction. The resources required to undertake the research is an important criterion; a vital resource relates to the research community and issues such as capacity, the researchers' interests and the availability of funds.

The potential outcome of research is another criterion and can be assessed by the appropriateness of the methodology, how well the research will be conducted, cost effectiveness, the ethical acceptability of the research and the feasibility of the proposed intervention (Frenk 1995).

A criterion that plays a role in prioritisation of health research is the time focus of the research. This includes the estimated time until the benefits of the research are realised and to what extent the research is aimed at the health problems of the future. Another way of looking at the time-related criteria for research priority setting is whether the research addresses long-, short- or medium-term health problems.

Another important criterion for developing countries like South Africa is whether the focus of the research is on a pre- or post-transitional health problem (ENHR 1991[a]). In other words does the research focus on, for instance, the infectious diseases of the poor or does it focus on the health research demands of the more affluent sectors of the population. It is essential that a balance between the two foci be maintained.

The American National Institutes of Health (NIH), lists five major criteria for the allocation of research funds: public health needs, the scientific quality of research, the probability of success, the maintenance of a diverse portfolio and the maintenance of an adequate scientific infrastructure (Gross et al. 1999).

2.1.7 COMBINING CRITERIA

Somehow all selected criteria for health research prioritisation need to be taken into account to establish the most appropriate priority list for health research. There is a need to operationalise the criteria and define these in detail. "In practice it is easier to apply the criteria when they are in the form of specific questions" (Tan Torres 1997 P 35). Friedman (ENHR 1991[a]) goes as far as proposing an explicit formula to combine selected criteria as a method of calculating the priority of the health problems. This quantitative approach remains untested. However, Varkevisser *et al.* (1991) have developed a rating scheme for prioritising health systems research which combines seven criteria with equal weights.

Tan Torres has suggested that a deliberate decision needs to be made as to whether equal weights for selected criteria are used (Tan Torres 1997).

The criteria should, as far as is possible, be independent of each other in order to minimise the effect of 'double counting'. Examples of interrelated criteria are the magnitude and urgency of the problem or the interaction between magnitude and the expected impact of the intervention (ibid). The application of certain criteria can yield conflicting results such as the criteria of equity and cost-effectiveness. Clear definitions of the criteria and delimitations should be agreed upon by decision-makers (ibid).

Janovsky and Cassels (1996) examine the idea of a common standard for assessing all health research priorities across all perspectives. They question whether different types of health-related research can be fitted into the same framework and whether decisions between competing demands can be made objectively. They conclude that it is not possible and recommend that a systematic approach within each area is needed and that the criteria for each may be different.

2.1.8 STEPS USED BY THE AD HOC COMMITTEE FOR PRIORITISATION

In 1994 the Ad Hoc Committee on Health Research Relating to a Future Intervention Options was established under the auspices of the World Health Organisation. It reviewed the global research priorities for developing countries building on the World Bank Development Report (World Development Report 1993). Equity was included in this exercise by targeting the needs of developing countries.

The Ad Hoc Committee (Investing in Health Research and Development 1996) used both the health problem approach and the health systems approach in separate exercises.

2.1.8.1 Health problem approach

In the health problem approach the first step was to identify major health problems by calculating the scale of the problems using the innovative DALY measure. The DALY combines the burdens due to mortality, morbidity and injuries. The second step was to identify why the disease burden persists, whether it was the result of (a) lack of knowledge

about the disease and its determinants, (b) lack of tools, (c) failure to use existing tools efficiently or (d) some combination of these reasons. Using additional data on cost-effectiveness and judgement of field experts on the proportion of the population receiving effective interventions, a rectangle representing a specific disease for a particular region or globally can be produced. The subdivisions within the rectangle break down the burden into different portions. These subdivisions are:

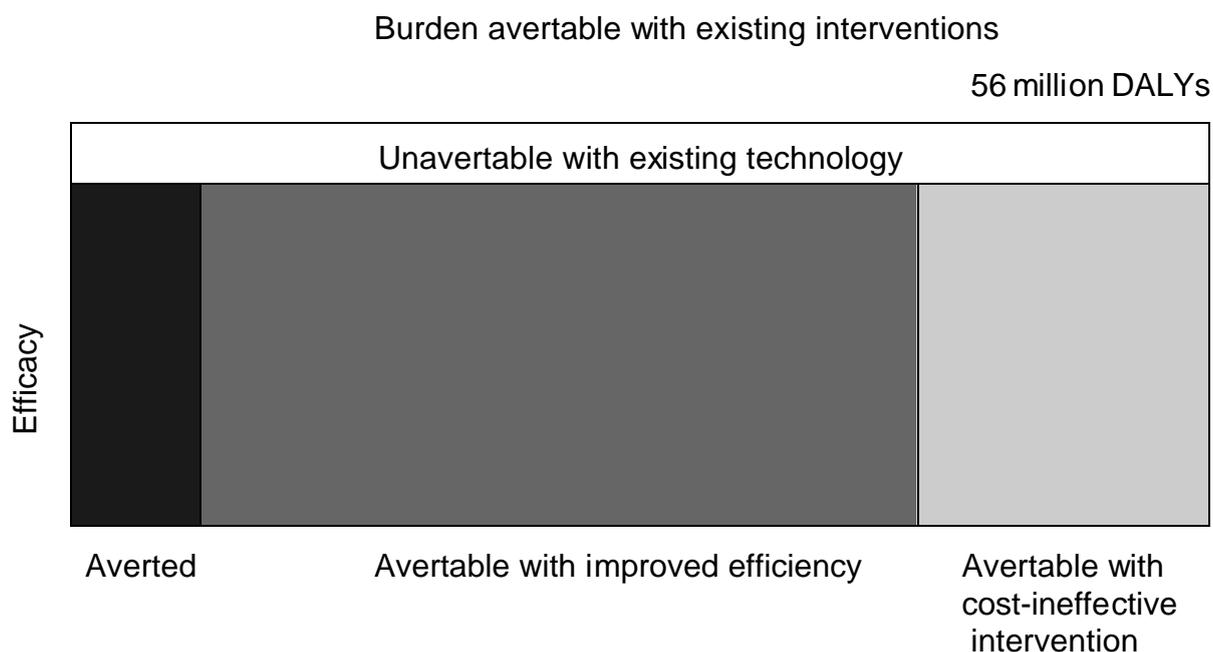
- “what portion of the total burden of each disease or condition is now being averted;
- what could be averted now with better use of existing cost-effective interventions;
- what could be averted now, but only with interventions that are not cost effective; and
- what cannot be averted with existing interventions but require new ones” (ibid).

This analysis is depicted in Figure 7, below, with an example from the report of the Ad Hoc Committee, showing the burden that is avertable with existing interventions for tuberculosis (TB). “The analysis is intended to identify where the greatest needs lie and thereby guide assessment of the priorities for different types of research” (Investing in Health and Development. Report of the Ad Hoc Committee 1996 P 6).

The procedure for this example can be summarised as follows: Step one identified TB as a major health problem. Step two involved analysing the reasons for its persistence under the three broad headings: (a) lack of knowledge of the disease or its causes (b), lack of tools to prevent or treat it, and (c) failure to use existing tools effectively. As (a) the cause of TB and the predisposing factors for the disease are largely known, its large scale persistence must therefore lie either in (b) a lack of tools or (c) inefficient use of existing tools or both.

Further analysis in terms of the subdivisions of the rectangle led to the conclusion that research and development efforts need to be divided between biomedical research to devise new interventions and operational research to make existing interventions more efficient.

FIGURE 7: Analysing the burden of tuberculosis to assess research needs



Effective coverage

Note: The total DALY figure represents the number for this condition in 1990 plus an estimate of the number then averted through existing interventions

Source: Investing in Health Research and Development. Report of the Ad Hoc Committee (1996)

The above analysis is an integral part of step two of the Ad Hoc Committee system which is, identifying why the disease burden persists. The use of the rectangle is a way of analysing the burden of a health problem in terms of identifying research needs. This is also part of step two in the planning cycle, (Figure 5), which follows the situational analysis, i.e., to remedy the situation by determining priority health research. While this analysis cannot offer precise analysis of need, it indicates “a sense of the *relative* distribution of the effort required” (ibid P 6).

Step three involves judging the adequacy of the knowledge base. This involves judgement on whether the research community has sufficient information to proceed with the development of new interventions or whether more strategic research is needed. Step four assesses the cost-effectiveness of the future interventions and whether the intervention can be developed soon for a reasonable outlay. Step five examines what has already been done about the problem, i.e. what resources had already been allocated to the

problem and whether resources would have been better utilised elsewhere. Thus, in a stepwise manner, the criteria of magnitude, knowledge gap and efficiency were incorporated into the prioritisation process.

2.1.8.2 Health systems approach

The Ad Hoc Committee recognised that the focus on specific health problems was not adequate to inform health policy. While specific policy or health system issues emerge in a health problem approach, the cross-cutting issues do not achieve the cumulative importance they may deserve. Research priorities in these areas were identified using a completely different process. Comprehensive review of both lay and expert consultation was used to identify research priorities for the demand and the supply side of the health system.

It would appear that the Ad Hoc Committee made use of Janovsky and Cassels' (1996) suggested framework that incorporates three sets of factors. Firstly, there is a need to assess the perceived importance of the topic; this relates to the policy objectives of equity, efficiency or responsiveness to users. Secondly, even if the topic is considered to be important, it is necessary to determine whether the proposed research will advance the current state of knowledge. Thirdly, the research methods proposed should generate information that is useful to policy makers. Thus, in the health system approach, a stepwise process was used to combine equity, efficiency and knowledge gap and the acceptability of the intervention.

2.2 CONCLUSION

A myriad of the factors that impact on health and guide the choice of appropriate intervention decisions on evolving health problems is presented as important background for the process of setting research priorities. Recognition is given to the restricted focus on the methods, of prioritisation and not the full analysis of the policy process.

In this chapter, two extreme methods for setting priorities, the rational and the incremental were identified. Realistic rational planning is recommended as a method of analysing

priorities as it has aspects of both extremes, combining technical skills with a recognition of the political process.

From the literature, it was seen that there are basically two orientations for analysing health research, a health problem approach or a health system approach; both are important. Leading on from these approaches, two useful frameworks for analysing and classifying research were identified; these in turn linked health research to scientific disciplines. The resulting classification provides a useful framework for organising health research. This incorporates the focus of research, identifying the purpose, as well as the type of research, which may be useful for describing resource allocation.

No matter what approach is used to identify health research needs, there is a need for the identified health research priorities to be ranked. This part of the prioritisation process utilises various criteria which represent important underlying values. The step-wise system for prioritisation of the Ad Hoc Committee is presented. This system employs different approaches for priority setting for health problems and health systems. This dual approach is comprehensive and is valuable as it is a systematic and transparent exercise that can be replicated.

However, it is important to note that the political process strongly influences what research is ultimately carried out. This political process, whilst alluded to throughout the analysis of priority setting, has not been discussed in detail.

CHAPTER 3
MEASURING HEALTH OUTCOMES

“Can you do Addition?” the White Queen asked.
“What’s one and one?”
“I don’t know,” said Alice. “I lost count.”

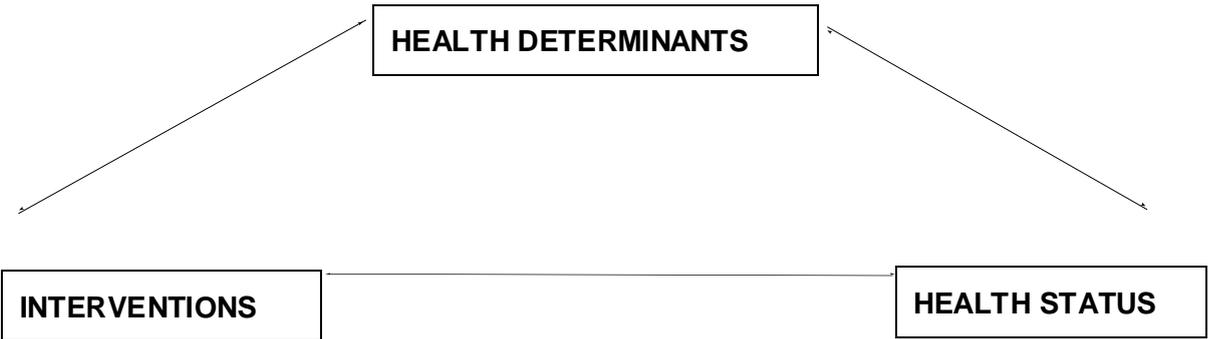
(Carroll, 1872)

3.1 HEALTH STATUS

Before going on to a detailed discussion of measurement of health outcomes, it is important to conceptualise what is being measured. Health status needs to be examined in more detail in order to emphasise the complexity of health outcome measures.

Figure 8 is a simple model of health status showing it as being the result of health determinants and interventions. Health status is defined through these two factors individually and as a result of the interaction between them. Health outcome measures reflect various facets of health status. (Figure 8 is a schematic version of Figure 4 in Chapter 2.)

FIGURE 8: The relationship between health status, determinants and interventions



Source: Lerer 1996 personal communication

Health determinants can be labelled proximal (direct) or distal (indirect). Smoking is an example of a proximal determinant; more distal determinants would be the social,

demographic and economic factors promoting tobacco use. “Distal determinants are mainly in the macro-economic, educational, environmental, demographic and health arenas” (Lerer *et al.* 1998 P 9). “Distal determinants are considered to be the driving forces of health status” (ibid P 12). “The effects of distal determinants are often, but not invariably, mediated through proximal determinants” (ibid P 9).

Proximal determinants are regarded as direct causes of changes in health status. Many proximal determinants of health status can be prevented “(through health education and promotion) and regulated (through fiscal and legislative measures)” (Lerer *et al.* 1998 P 15).

The relation between determinants and health status is largely indirect. It is modified by factors such as class, gender, education and socio-economic disparity” (Lerer *et al.* 1998 P 18).

3.2 MEASUREMENT

It is important to consider measurement, *per se*, as there have been extensive advances in the development of summary health measures that have not been comprehensively documented. Furthermore, the summary measures of health are not strictly objective and therefore it is necessary to analyse the values and social preferences inherent in them.

The DALY is a relatively new measure that has been used as a measure of global burden of disease and for global comparative assessments in the health sector (WDR 1993; Murray 1994). Furthermore, in terms of health and development, the DALY has been an adjunct tool in determining future research intervention options. (Investing in Health Research and Development. Report of the Ad Hoc Committee 1996). There has also been increasing utilisation by the WHO of summary measures to assess performance of health systems. An example of the latter is Disability Adjusted Life Expectancy (DALE), (The World Health Report 2000).

Measurement is more than the simple act of counting and adding data. There are also no physical devices available to measure constructs in the social and behavioural sciences.

According to the widely quoted WHO definition, health is defined in very broad terms. It is not seen to be simply the absence of disease but a state of well-being at all levels of human existence (Investing in Health Research and Development. Report of the Ad Hoc Committee 1996).

Measures of health status must address the underlying issue of values. The notion of health versus illness or disability is a value judgement. Whatever is used for defining health, be it, biological, psychological, social or cultural criteria, “there are existing values that identify deviation from an acceptable state of being, reflecting peoples’ deepest aspirations and fears” (Patrick and Erickson 1993 P 19). In order to measure health, this conceptual framework needs to be made operational. The measurement of health proceeds by assigning numbers to health states and manipulating these numbers. Indicators of health status define quantities that describe aspects of health. These indicators are considered to be either ‘negative’ or ‘positive’ measures. An example of the former is mortality and an example of the latter is life expectancy. Although the ultimate goal is to promote good health, the primary focus of most health measurements is disease or ill-health, because of the difficulties of measuring health. However, with the current emphasis in public health shifting to health promotion, more attention has been given to positive indicators such as social and mental well-being.

The more usual measures of mortality and morbidity are inadequate for assessing people who are not ill but have some limited function which affects their everyday life. During the last few decades particularly, new health indicators or health outcome measures have been developed to assist in the analysis of the consequences of disease. The concept of morbidity has been extended to incorporate the personal and social consequences of diseases as well as quality of life measures.

The various measures of health outcome will be presented from an historical perspective. In particular, the combined indicator of mortality and non-fatal outcomes, the DALY, will be examined in some detail and compared to other related measures. The intended uses of the measures, whether for assessment, comparison at regional or national level, or planning will be discussed. The usefulness of the DALY to aid health research prioritisation will be highlighted.

3.2.1 MEASURES OF MORTALITY

The measurement of health status dates back to Babylonian times when mortality rates were used to assess the health status of the population.

Life expectancy is an index of mortality. It can be estimated from a life table of the population and reflects both childhood and adult mortality. An expectation of life must always be related to people at a particular age. Life expectancy is usually the measure of the expectation of life at birth.

A crude death rate is the number of deaths in a given time period divided by the population at risk. Adjusted rates are hypothetical summary rates constructed to permit fair comparisons between groups differing in some important characteristic, such as, age. Age-standardized rates are constructed by applying the rates for each age group to a standard population.

Detailed rates for specific groups are needed to analyse epidemiological aspects of disease and population dynamics. For example, the infant mortality rate, the number of infant deaths in a year divided by the number of live births in the year is an important indicator. Child mortality - the probability of a child dying before the age of 5 - is also used as a proxy measure of the health status of the population.

Measures of adult mortality, such as the 45Q15 are also important indicators of population health status. The 45Q15 is the probability of a 15-year-old dying before the age of 60, and describes the level of premature adult mortality. The 35Q15, (the probability of a 15-year old dying before the age of 50), is an important indicator of young adult survival which is changing rapidly due to the AIDS epidemic.

The concept of time lost to mortality, rather than death rates, was introduced in the late 1940s (Dempsey 1947). Subsequently, there have been a wide variety of methods proposed to measure years of life lost. Allied concepts include premature mortality and preventative mortality. An example of a measure that introduces a time dimension to the

evaluation of health is Years of Potential Life Lost (YPLL). Potential years of life lost are calculated by defining a limit to life and determining the years lost due to each death as the limit minus the age at death. The potential limit to life is an arbitrary figure ranging from about 60 to 85 years. YPLL takes account not only of the number of deaths from a disease but also the number of years that people might have continued to live on average compared with their counterparts (Public Health Status and Forecasts P 43).

3.2.2 MEASURES OF MORBIDITY AND NON-FATAL OUTCOMES

Disease-specific measures of morbidity date from the nineteenth century. Two indicators of morbidity are incidence and prevalence.

Incidence rates are the number of new disease cases over a period of time divided by the population estimate. Incidence rates are a direct indicator of the risk of a disease.

Prevalence rates measure the number of people in a population who have a disease at a given point or period in time divided by the population estimate. Prevalence rates capture both incidence and duration of a disease.

These indicators relate to the etiology of diseases and recently, more attention has been given to the measurement of morbidity and non-fatal health outcomes and the associated quality of life. This shift is in part due to the preponderance of chronic diseases, particularly in the industrialised countries with aging populations. Developing a measure of disability is exceedingly difficult: One reason for this is that, unlike mortality, there are many dimensions to disability such as physical disabilities, pain, discomfort, emotional distress and loss of dignity (Morrow and Bryant 1995).

Three important conceptual frameworks are used for non-fatal health outcomes (Goerdts *et al.* 1996). According to Murray (1994 P 10), these have developed in isolation as a result of “disciplinary focus, geographical and institutional locus and types of health systems.”

The different strands include:

1. The International Classification of Impairment, Disability and Handicaps (ICIDH) classifies three dimensions for the consequences of disease. *Impairment* is defined

at the level of the organ system, *disability* is the impact on the performance of the individual while *handicap* includes the overall consequences which depend on the social environment. There are many valid criticisms levelled at the ICIDH. These include its inaccessibility and unnecessary complexity as well as the absence of a recommended assessment schedule. Furthermore, it has been recommended that it be updated (Katzenellenbogen 1991). A revised version of ICIDH-2 (pre-final) has emphasised health and health related domains.

2. The health-related quality of life approach, (HRQL), was developed mainly in North America. The indicators are weighted aggregates of variables measuring physical, mental and social function. They include both objective and subjective measures of functional status and well-being.

A range of instruments for measuring the incidence or prevalence of health states in the community have been developed in the HRQL field. These include generic instruments that provide a profile of health status relevant to quality of life (QOL) such as the WHOQOL (WHO 1993) and the EuroQol (EuroQol Group 1990). More recently, the Evidence Cluster of WHO has developed a tool which is being piloted.

The theoretical bases for defining health and quality of life states are the theories of positive well-being and quality of life from psychology and functionalist theory from sociology and anthropology (Patrick and Erickson, 1993 P 60).

3. An utilitarian framework underlies most of the work on health economics. In this theory, non-fatal health outcomes are important only to the extent to which they alter an individual's utility. Utility in economics is synonymous with the satisfaction of individual preferences. The focus is on the measurement of preferences rather than on the measurement of characteristics of health that individuals' value. The analysis of utility includes measures such as PYLLs, DALYs or QALYs, which "explicitly introduce one or more subjective parameters in order to value outcome" (Musgrove 2000 P 110).

3.3 SUMMARY MEASURES COMBINING MORTALITY AND NON-FATAL OUTCOMES

Extensive research has been carried out to develop more general measures of non-fatal health outcomes that are commensurate with time lost due to premature mortality. Since Sullivan's (1971) proposal in the late 1960's of a composite index of health status that incorporates mortality and morbidity, there has been much debate on the value of these single indicators (Murray 1994). However, there are no comprehensive overviews of these measures. This section attempts to provide such.

Composite measures of health are invaluable for comparing different health conditions and for monitoring health services and research. It is difficult to compare different health conditions directly as each has different ill-effects, with the resulting problem of comparing 'like with true like'. As a result there has been a number of attempts to create composite measures which assign values to different combinations of health states such as, death, pain and disability.

Early work on composite health status indicators was that of the Ghana Health Assessment Project Team (1981). This work was a first attempt to evaluate the burden of disease due to disability and premature mortality by cause for an entire population. The measure, *healthy days of life lost (YHLL)*, was used with the assumption that days lost to death, being permanently disabled or temporarily disabled should be valued equally. This composite indicator combines morbidity and mortality to provide quantitative measures of losses from particular diseases and gains from particular interventions.

3.3.1 QALY: QUALITY ADJUSTED LIFE YEAR

Torrance *et al.* (1972) developed a measure in which health states between perfect health and death are weighted by the utility to the individual of time spent in each of these states. Zeckhauser and Shephard (1976) were the first to label such a measure of utility or preference-weighted time as QALYs. The term QALY refers to a time-based measure which includes life expectancy and non-fatal health outcomes where time spent with non-fatal outcomes is adjusted by a preference weight. QALY is a rubric for a family of such measures; there is no standard method for calculating QALYs.

The QALY measures years of survival weighted for the quality of life, which people may be expected to have in the context of different states of illness. Attempts to quantify the quality of life have been conducted in some cases by experts and in others by communities (Barker and Green 1996). QALYs have been used extensively in cost-effectiveness studies but have had limited use in describing the comparative burden of different conditions.

3.3.2 DALY: DISABILITY ADJUSTED LIFE YEAR

The 1993 World Bank Development Report and the Ad Hoc report (1996) make extensive use of the DALY as a composite measure of disease burden. William Foege (1994) sees the DALY as a major public health development of the past century. He states that the DALY concept has the potential to revolutionise the way in which we measure the impact of disease. The DALY combines years of healthy life lost from disability with those lost from premature death. DALYs were calculated for over one hundred specific diseases for eight demographic regions worldwide.

The DALY is calculated by adding Years of Life Lost (YLL) and the Years Lived with Disability (YLD). The YLL is determined using the West model life-table to determine age- and sex-specific life expectancies. This is one of four key values or social preferences that are incorporated in the DALY.

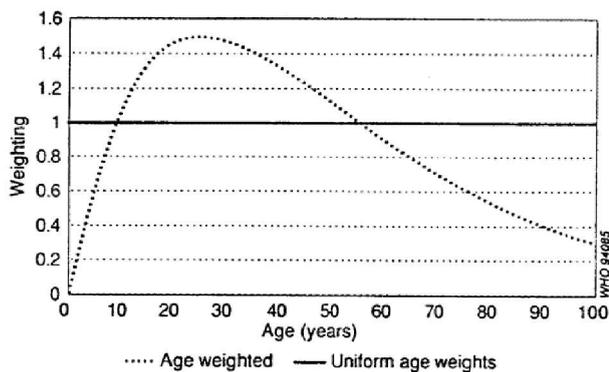
The YLD is calculated on the basis of the incidence and duration of conditions resulting in non-fatal outcomes and are weighted according to the severity of the disability of the sequelae. In this way, another explicit value is attached to the time lived with a disability to make it comparable to time lost due to premature mortality.

In contrast to the Ghana study (1981), the DALY calculations for the measurement of disability use a standardised method for defining, measuring and weighting disability. Health professionals from around the world were asked to evaluate the disability for the average individual with the condition described, taking into account the average social response or milieu and using the person trade-off methodology. Individuals were asked to choose between curing a certain number of individuals in one health state and another

number in a different health state. The methodology elicits the point at which the individual is indifferent to the two choices being offered. At this point the outcomes are equivalent and a weight is derived (Murray 1994). Based on the results from the person trade-off protocol, the spectrum from perfect health (0) to death (1) was divided into six arbitrary classes. Highly consistent results were obtained from the various groups that participated for the disability severity weights for the 22 indicator conditions. Each class is exclusively defined by the range of disability weights and contains two or three indicator disorders, that act as benchmarks for the definition of each class.

The third explicitly social preference incorporated in the DALY, is the value of time lived at different ages. This is shown in Figure 9, which depicts the age-weight function. The middle age group, 9-54 years, is weighted more than the extremes.

FIGURE 9: Age-weight function



Source: Murray (1994)

The fourth social value incorporated in the DALY relates to time preference and involves, the choice of a discount rate for future loss. Discounting implies a greater preference for time lived now than at some time in the future. This is particularly important in the context of cost-effectiveness assessments where future costs are discounted.

The general underlying concepts and specific values as well as the justification of certain assumptions used in the formulation of this measure are made explicit.

3.3.3 HeaLY: HEALTHY LIFE YEARS

Another new composite measure is the Healthy Life Years (HeaLY), which is a measure of healthy life-years lost, reformulated from the Ghana Health Assessment study data. Details are given in Appendix 2.

It is defined as “a composite measure that combines the amount of healthy life lost due to morbidity with that attributable to premature mortality” (Hyder *et al.* 1998 P 196). The defining characteristic of the HeaLy is that it is based on the incidence pattern within the conceptual framework of the natural history of disease rather than the juxtaposition of current mortality and the current incidence patterns.

3.3.4 DFLE: DISABILITY FREE LIFE EXPECTANCY

The principle of the calculation of Disability-Free Life Expectancy was postulated in the early 1960s. However, the first method of calculation of such a measure was proposed by Sullivan in 1971. The institutionalisation rate (generally from a recent census) and the prevalence of various states of functional disability (from national health or disability surveys) are incorporated with the years lived at various ages by the population of a life table. The period life expectancy for the modified table is calculated in the traditional manner yielding the value of Disability-Free Life Expectancy. The advantage of Sullivan’s method of calculating health expectancy is that mortality and disability data are treated separately and the data necessary for the calculations are available. The problem with this method is that it approximates the period prevalence by the observed prevalence within the population; it is not really a period indicator (Goerdts *et al.* 1996).

3.3.5 DALE: DISABILITY ADJUSTED LIFE EXPECTANCY

The DALE is calculated using a weighted number of years lived with disability added to the years of healthy life lived at a specific age.

3.4 COMPARISONS OF COMPOSITE MEASURES

3.4.1 QALY AND DALY

The QALY can be considered to be a precursor of the DALY. The DALY like the QALY allows both fatal and non-fatal outcomes to be combined in a single indicator. However, the QALY is a measure of health rather than ill-health.

Marrow and Bryant (1995) point out that with the QALY, the focus is on assessing individual preference for different non-fatal health outcomes that might result from a specific intervention and that the DALY was developed primarily to compare relative burdens among different diseases and among different populations.

The DALY is considered to be a simpler and more 'objective' measure than the QALY as it is concerned with the severity of disability rather than the quality of life.

3.4.2 HeaLY AND DALY

The HeaLY differs from the DALY in that no differential is given to the value of life according to the age at which life is lived. Another difference is that discounting is integrated into the DALY formula, whereas with the HeaLY, discounting is done separately.

The major purpose of the HeaLY formulation is the assessment of the effects of health interventions and not attributing loss to specific diseases. This is facilitated by the HeaLY formulation being based on life lost to disability and death for all disease with onset in a given year. The effectiveness of interventions are considered on the basis of current incidence patterns. For the DALY measure, mortality and disability are considered for all deaths in the current year regardless of when the onset of diseases occurred.

3.4.3 DALY AND DALE

The DALY is a measure of the health gap whereas the DALE is a summary measure of health. The health gap is the difference between the actual health of a population and some reference status. DALYs are preferable to the DALE, the life expectancy in

different classes of disability when the burden of non-fatal outcomes and premature mortality needs to be broken down into the burden attributable to various diseases, injuries or exposures. This situation is analogous to cause specific death rates versus the relative utility of life-expectancy (Murray and Lopez 1997[b] P 1352).

3.4.4 DFLE AND DALE

Disability-Free Life Expectancy, (DFLE) and Disability-adjusted life-expectancy, (DALE), are two measures of health expectancy. DFLE is a calculation of expected length of life without disability. The DALE is calculated in the same way as the DFLE at birth, with the DFLE, the number of years lived at a specific age is obtained from a life table. The DFLE measure attributes zero weights to estimates of life expectancy in different health states. DALE calculations are estimates of life expectancy for different health states adjusted for the GBD disability severity weights (Life Expectancy minus the DALE equals the severity-adjusted expectation of disability). Both are useful ways to summarise the health status of a population. Further examples include, Impairment Free Life Expectancy (IFLE) and Handicap Free Life Expectancy (HFLE) and are considered to be positive health indicators.

International comparisons of DFLE and other health expectancy measures have been hampered by differences in calculation and definition. However, the new WHO Report 2000 which incorporates estimates of DALE for each country is likely to create a standard approach that will overcome this problem (WHO 2000).

3.5 COMPARISON OF DALE VERSUS LIFE EXPECTANCY

The World Health Report 2000 has focussed on evaluating the performance of health systems. Data from this report for DALEs and Life Expectancy for males and females for the 191 WHO Member States was analysed, using regression analysis. DALEs were regressed on Life Expectancy. The results, as expected, are very highly correlated. This can clearly be seen in Figures 10 and 11.

Based on the regression model, the DALE is on average 10 years less than the Life Expectancy.

**FIGURE 10: Graph of disability adjusted life expectancy against life expectancy:
Males**

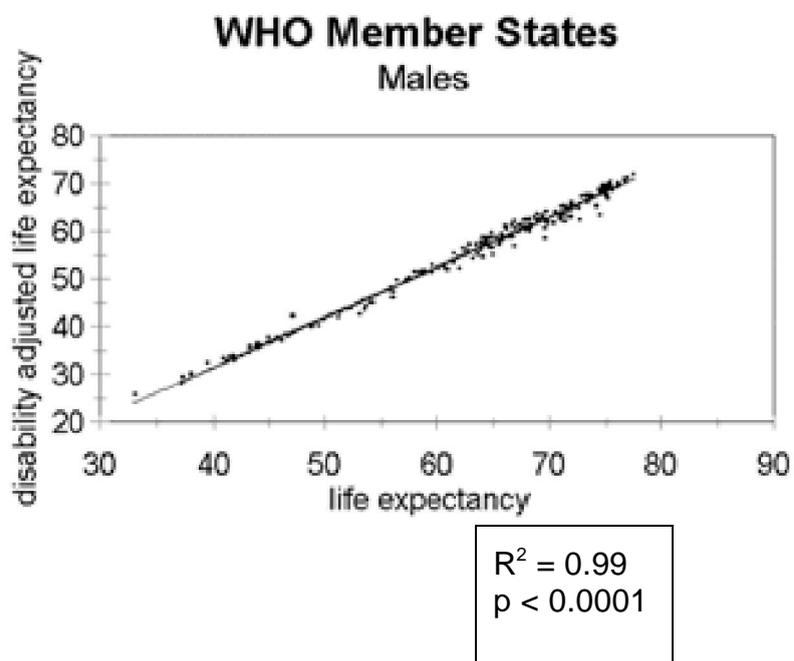
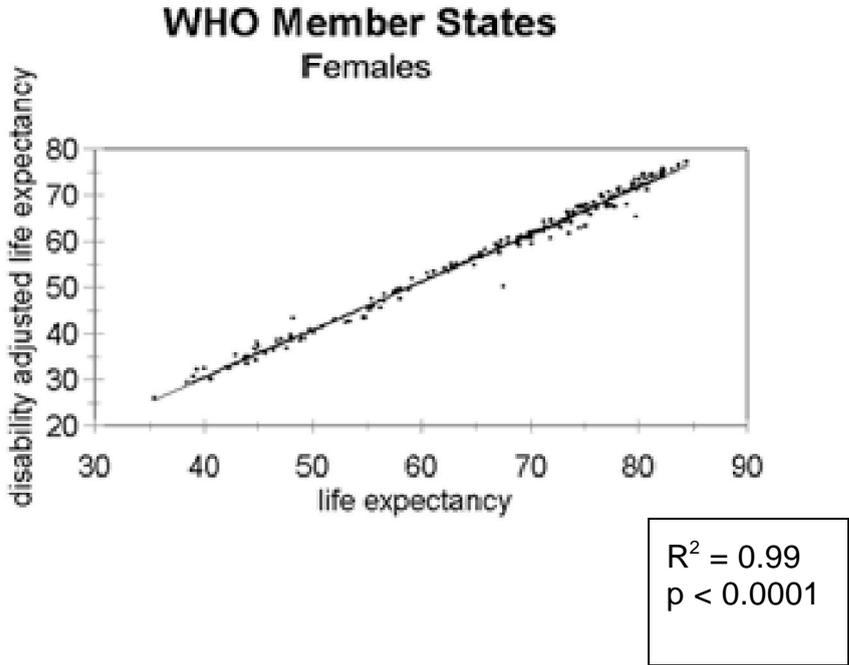


FIGURE 11: Graph of disability adjusted life expectancy against life expectancy: Females



3.6 COMPARISON OF DALY VERSUS MORTALITY

Roughly two thirds of the global burden of disease measured by DALYs, is due to premature death and one third is due to disability (Jamison *et al.* 1995). The morbidity component of the DALY is generally more difficult to quantify than mortality due to the number of parameters and limited data. Hence it is important to understand what gets added by the morbidity component, (YLD), of the DALY over and above the mortality component, (YLL). The use of the DALY as opposed to mortality data only for the setting of health priorities is explored in the following section; this is integral to the question as to whether one needs dally with the DALY.

Some medical classifications have only a mortality component, for example suicide, whereas others have negligible excess mortality and a large non-fatal component such as some psychological disorders. A whole spectrum of differing mortality/morbidity ratios for different diseases and injuries lie between these two extremes. The relationship between mortality and non-fatal burden is investigated by means of linear regression analysis. In addition, in order to examine mortality and the DALY, YLLs were expressed as a percentage of DALYs for all diseases for SSA that were included in the regression analysis.

3.6.1 DATA

Estimates from the Global Burden of Disease study for Sub Saharan Africa for DALY and YLD values for each disease are used (Murray and Lopez (1994). The YLL values could readily be obtained by subtraction from the reported DALYs. Table 3 below shows the 14 diseases or injuries that were excluded from the analysis as they had either a negligible mortality component or a negligible non-fatal component. These conditions clearly do not have a relationship between the YLDs and YLLs.

Table 3: Sub-Saharan African diseases and injuries which have either YLDs or YLLs less than 1000

| | DISEASE OR INJURY (ICD 9 CODE) | BOD Category | YLD (1000) | YLL (1000) |
|----------------------------------------------------------------------|----------------------------------------------------------------------------------------|-------------------------|-----------------------|-----------------------|
| Conditions with mortality but little morbidity or disability | | | | |
| 1 | Hypertension complicating pregnancy, childbirth and puerperium (642 MINUS 642,4-642,6) | I | - | 204 |
| 2 | Other Neoplasm (210-239) | II | - | 453 |
| 3 | Skin disease (680-709) | II | - | 113 |
| 4 | Drowning (E910) | III | - | 1554 |
| 5 | Self-inflicted (E950-950) | III | - | 1686 |
| Conditions with morbidity and disability but little mortality | | | | |
| 1 | Trachoma (076) | I | 901 | - |
| 2 | Major affective disorder (-----) | II | 1647 | - |
| 3 | Post traumatic stress disorder (-----) | II | 505 | - |
| 4 | Glaucoma related blindness (365) | II | 171 | - |
| 5 | Cataract related blindness (715) | II | 1130 | - |
| 6 | Osteoarthritis (521.0) | II | 223 | - |
| 7 | Dental carries (523) | II | 436 | - |
| 8 | Periodontal disease (520) | II | 417 | - |
| 9 | Edentulism | II | 41 | - |

(Source: Murray and Lopez 1994)

I Communicable, maternal and perinatal

II Noncommunicable

III Injuries

- indicates less than 1000 YLDs or YLLs

3.6.2 METHODS

The four graphs and the statistics were obtained using the Advanced Regression programme of the spreadsheet Quattro Pro (Version 6 1997). The graphs have the YLD as the dependent variable and the YLL as the independent variable. Both measures have

been transformed using a natural logarithmic scale of the measure plus one, so as to have a more meaningful spread of the data that was more normally distributed. This was necessary as there were some outlying values. Linear regression lines were fitted with $\log(YLD + 1)$ as a function of $\log(YLL + 1)$ for All diseases and the three sub-groups of: Communicable and Maternal, Non-Communicable and Injuries. These correspond Figures 12, 13, 14 and 15 respectively. There are 68 observations with 20 observations for Communicable and Maternal, 41 observations for Non-Communicable diseases and 7 observations for Injuries. The correlation coefficient (R^2) was used to describe the extent of the relationship between the transformed DALY and YLL. The significance of the correlation is assessed using the p-value.

FIGURE 12: Graph of years lived with disability against years of life lost:
All Diseases

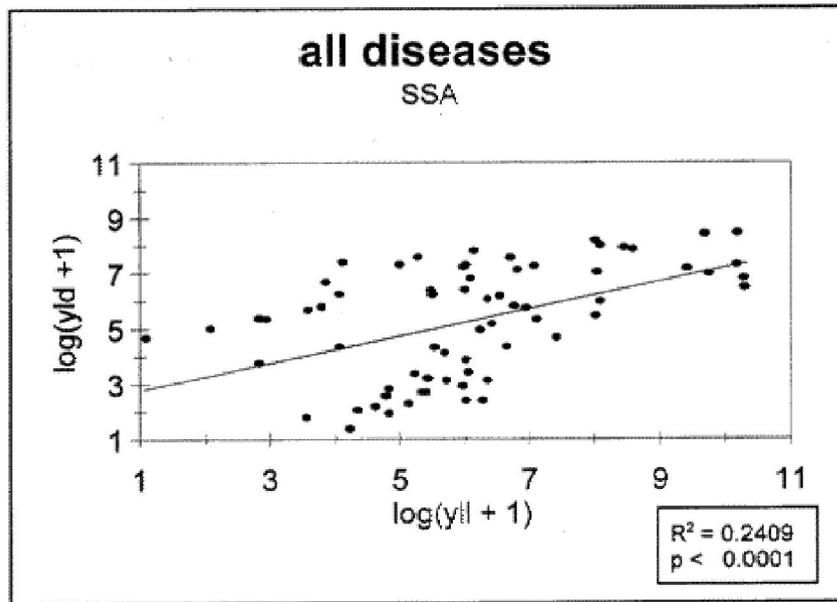


FIGURE 13: Graph of years lived with disability against years of life lost:
Communicable Diseases

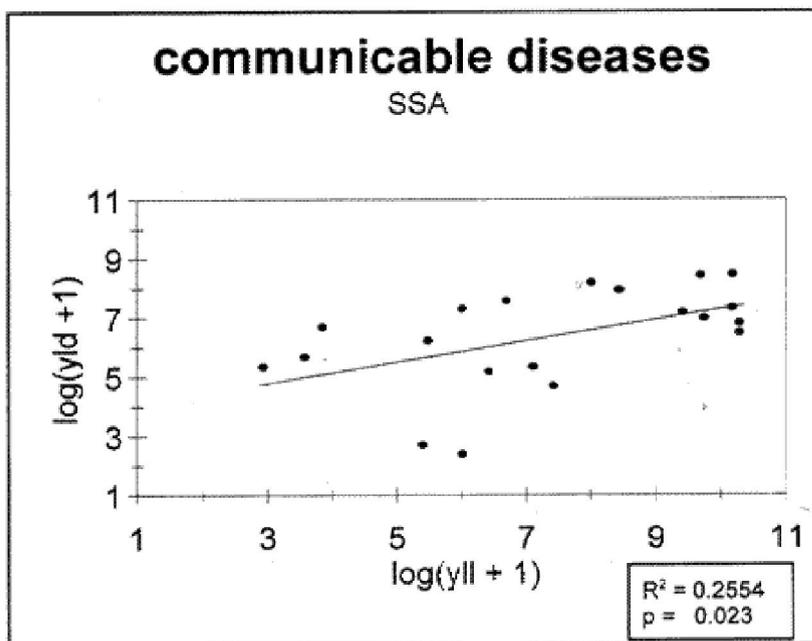


FIGURE 14: Graph of years lived with disability against years of life lost:
Non-Communicable Diseases

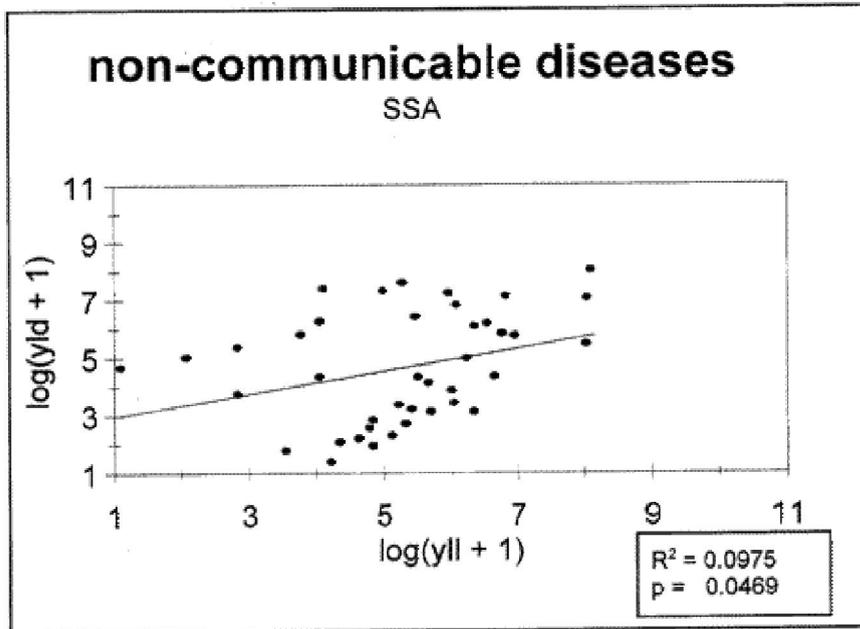
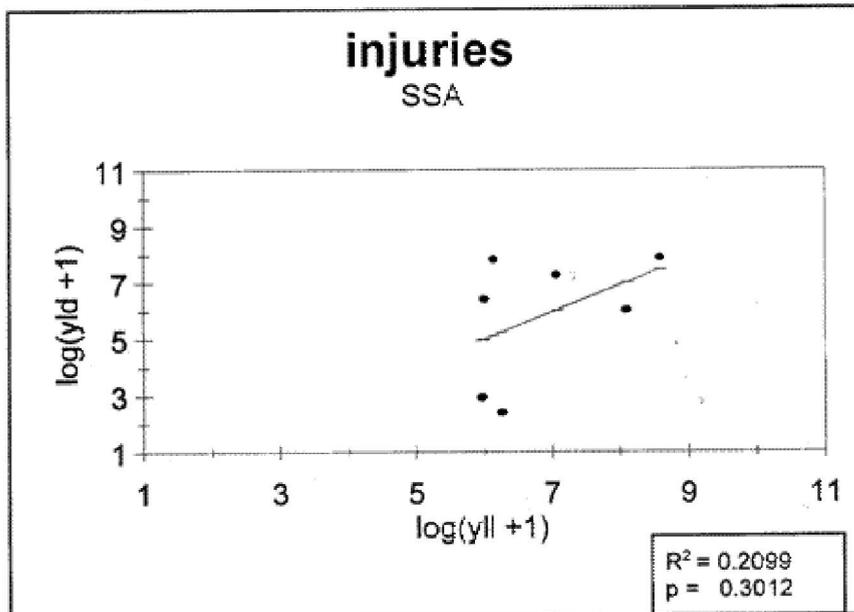


FIGURE 15: Graph of years lived with disability against years of life lost:
Injuries



3.6.3 RESULTS

For the DALY versus YLLs, for All Diseases, the correlation for YLDs regressed on YLLs is, $R^2 = 0,2409$. The correlation is highest for Communicable Diseases with $R^2 = 0,2554$. The lowest correlation, $R^2 = 0,0975$, is for Non-Communicable diseases. The correlation is 0,2099 for Injuries. The probability values (p values), range from $p < 0,0001$ for All Diseases, to $p = 0,3012$ for Injuries. At the chosen probability level (95%), there are 3 statistically significant results, i.e. they cannot be attributed to chance. The probability value for Injuries is not less than 0.05. It should also be noted that Injuries is the smallest sub-group, with only 7 values.

However there is considerable variation and the average percentage value for YLL/DALY is 63,1%, mortality accounts for only 1,8% of the total burden for affective disorders while it accounts for 98,1%, for poisoning. While the diseases and injuries at both the extremes of the distribution of the YLL/DALY percentages, can be reasonably well identified, there is a wide range of values which cannot be easily identified with accurate predictions of the corresponding values.

These results suggest that mortality cannot be used to predict morbidity. Hence, the morbidity or non-fatal component would be most a useful additional health outcome measure especially for Non-Communicable diseases.

Although mortality is an important component for examining the burden of disease, morbidity cannot be ignored as it constitutes a relatively large portion of the burden of disease. Based on the calculation, on average up to 36% of the total burden can be attributed to morbidity.

3.7 CONCLUSION

The above analyses show that it is important to measure non-fatal health outcomes when considering burden of disease or health gap, as they constitute a large proportion of the burden of disease.

For the comparison of the DALE versus Life Expectancy, both correlation values approach unity, which represents perfect correlation. Thus, in the case of an overall summary of health, it would appear that life expectancy could be used as a proxy for DALE.

In the case of prioritising health research through the identification of health problems, it is important to analyse the health gap. It is therefore clear that it is important to take non-fatal outcomes into account and that mortality is not an adequate proxy measure.

CHAPTER 4

THE DALY AND SETTING PRIORITIES FOR HEALTH RESEARCH

4.1 THE DALY AS A MEASURE FOR SETTING PRIORITIES

The DALY as a measure of the health gap can be utilised in priority setting for research. However, since its development there have been many criticisms of the DALY. These criticisms relate to technical issues such as those concerning the quality of data used to calculate DALYs and more subjective or conceptual issues such as age and disability weights and discounting. According to Bobadilla (1996), the former can be remedied by relatively minor modifications to the original formula. He suggested that the conceptual criticisms can only be addressed once there has been more research on social preferences.

In particular, the DALY Review Group of the WHO's Advisory Committee on Health Research (ACHR) (1995/96) stated that the DALY in its present stage of development does not solve the problem of prioritisation and resource allocation. Notwithstanding the fact that the head of the WHO has endorsed the DALY (Brundtland 1999), an examination of the criticisms levelled by the ACHR and others, as well as the counter-criticisms, will help assess the DALY as a measure of ill-health and a tool for setting priorities.

4.2 TECHNICAL ISSUES WITH THE DALY

4.2.1 POOR QUALITY DATA

The data demands to estimate the DALY are extensive. However, the data required for the calculation per disease by age and sex is not always available. Even if reliable morbidity information on the incidence and prevalence of disease and injury are available, it is possible that data on the likelihood of sequelae and their severity and duration are not available. For the GBD study the best estimates of epidemiological indicators which include incidence, remission rates, case-fatality rates and the general mortality rate were obtained. This was facilitated by the use of a computer programme called DISMOD (Disease model) to assess the consistency of the data.

The review of the ACHR (1995/96) refers to the poor quality data utilised for the DALY formulations. The review points out that a substantial proportion of the data used in the GBD study has been generated by modelling or guesswork.

The problem is exacerbated for the SSA region where the estimates are considered to be based on an extrapolation from the 1% of the Sub-Saharan population covered by vital registration in South Africa. Cooper *et al.* (1998) asserts that the estimates for SSA do not help define the burden of disease for that region and cannot be compared with developed countries.

Murray and Lopez (1997[a]) respond to the problem of poor health information by pointing out that the use of the DALY to measure burden of disease indicates the strengths and weaknesses of existing health information systems. Furthermore, the GBD study makes use of DISMOD to derive internally consistent estimates of mortality, incidence and prevalence measures from the available epidemiological data. Through this process it is possible to identify information gaps and inconsistencies. It is argued that since decisions need to be made, it is advisable to attempt to make the best use of available data by developing coherent estimates.

4.2.2 INCIDENCE VERSUS PREVALENCE

As time has been chosen as the unit of measure, the burden of disease could be either an incidence- or prevalence-based indicator. Murray (1994 P 6), gives three reasons why an incidence perspective was chosen:

1. The method of calculating time lived with disabilities is more consistent with the method for calculating time lost due to premature mortality.
2. An incidence perspective is more sensitive to current epidemiological trends and will reflect the impact of health interventions more rapidly.
3. Measuring the incidence or deriving it from prevalence data and information on case-fatality and remission rates imposes a level of internal consistency and discipline, which would be missing with the uncritical use of prevalence the data.

It is, however, important to be aware of the consequences of this choice. For instance, the DALY measure discriminates against currently disabled people as those previously disabled will not be included in the DALY calculations (Legge lecture UWC 26/1/96). Furthermore, the choice of incidence data favours distinct rather than diffuse or chronic conditions (DALYs and Reproductive Health 1999).

4.2.3 PROBLEMS WITH COMPOSITE MEASURES

The ACHR states that another difficulty with the DALY is the combination of unlike elements, namely death and disability. Death and disability are on the same continuum linked by time. Anand and Hanson (1996) argue that one simply cannot have the two events on the same scale as they are incommensurable. Anand and Hanson (1997) state that with the DALY scale, death differs from disability merely by reducing human function to zero and Paalman *et al.* (1998) point out that there may be states worse than death.

In addition, by keeping disability and death data separate, the Review Group contends that it is easier to formulate more specific policies in the different countries. This would prevent the inevitably inexact estimates of disability from corrupting mortality data.

As far as the criticism that the separation of disability and death would make it easier to formulate specific policies for different countries, Murray and Lopez (1997[a]) pointed out that it is not possible to estimate the DALY without separate calculations for disability and mortality, thus making this information available for policy formulation.

4.2.4 VALIDATION

Another criticism which relates to technical issues with the DALY concerns the validation of the DALY as an indicator of health status. According to Sayers and Fliedner (1997), this validation process involves ascertaining that the behaviour of the indicator in response to random error and systematic bias in the raw data is acceptable. They contend that sensitivity analyses by Murray and Lopez (1997[a]) contributes nothing to validating the indicator.

4.3 CONCEPTUAL ISSUES WITH THE DALY

The general underlying concepts and specific values as well as the justification of certain assumptions used in the formulation of the DALY measure have been made explicit. Much of the criticism of the DALY has focussed on the social preferences or values included in the DALY. These include the unequal age weights, the discounting of future health years as well as the disability weights.

4.3.1 THE DALY AS A UNIT OF MEASUREMENT: VALUES

It is necessary to examine the underlying values of the DALY as well as whose values they represent. Anand and Hanson (1997) identify at least four distinct groups whose values are incorporated in the DALY used in the GBD exercise:

1. The social planner who specifies the burden of disease exercise and the DALY function used to measure it.
2. Various unspecified individuals for the age weighting function.
3. The weights for the six disability classes were chosen by a group of independent experts and the criteria used to establish the weights were not made clear (Anand and Hanson 1997).
4. The discount rate used is determined by the authors of the World Bank Report (Murray 1994) and is set at 3%. This is consistent with the long-term yield on investments. Anand and Hanson (1997) argue that yield on investment has little to do with discounting health outcomes.

The DALY measure of ill-health has a narrow focus as the quantity of ill-health experienced by individuals is represented through functional limitation and premature death only. Pain and suffering or reduction in well-being are not included in the DALY. Consequently, the DALY renders caring as discretionary and ineffective (Legge lecture, University of the Western Cape (UWC) 26/1/96). Legge argues that caring activities which express the compassion within a health system stand at risk of being discounted by policies based on

the assumption that value for money is defined solely in terms of cure or prevention (Legge 1993).

4.3.2 SOCIAL VALUES

4.3.2.1 Age-weighting

According to Musgrove (2000), age-weighting is the most controversial of the subjective parameters used in the calculation of DALYs. Murray (1996[a]) justifies the chosen age weights on the basis that several studies have shown a preference for saving young adult lives over those of young children or elderly people.

If viewed from a human capital framework, age-weighting might be justified in terms of differential productivity at different stages of life (Anand and Hanson 1997). However, Murray (1994) argues that he has not used a human capital framework as productivity weights do not adequately reflect human welfare. According to him, the productivity weights are not applied in a consistent manner and other human attributes linked to productivity such as education are not included in the weighting of time. Age-weights are justified in terms of social preferences. The social value of the middle-age groups is considered to be greater due to the responsibility for their dependants.

Murray can be perceived as being inconsistent in that he does not use productivity weights in the development of the DALY because of their 'obvious inequality', yet he appears to invoke what is essentially an economic cost-benefit argument to defend social time preference. However, Musgrove (2000) defends Murray by arguing that there is no inconsistency in rejecting an economic measure and then using age-weights that take into account the emotional loss of an individual's death to other people.

Paalman *et al.* (1998) contend that such values would be impossible to generalise to one functional formula and would depend on context-specific conceptions of human value.

Criticisms of the age-weighting function are not straight forward due to the confounding of age and disability that occurs with the DALY function. Barendregt *et al.* (1996) show that when comparing age-weighted and unweighted age-specific life expectancies, the age

range which becomes more important due to weighting is not 9-54 years but 0-27 years. This happens as expected years of life lost is an age-weighting system in itself, emphasising the young. The discounting of future years partly redresses the shift toward younger ages as discounting mostly affects life years lived at a higher age.

Murray and Lopez (1996[b]) in their response to criticisms of the incremental effect of age-weighting on YLLs, YLDs and DALYs agree with the findings of Barendregt *et al.* (1996) but contend, however, that the largest incremental change is closer to age 10 years. Their findings confirm the basic observation about YLL - that the interaction of duration of life lost, age-weighting, and discounting leads to a maximum YLL for a death during adolescence. Murray and Lopez (1996[b]) go on to criticise Barendregt *et al.* (1996) for concluding that their observations for YLL also applies to YLD. Murray and Lopez (1996[b]) state that this conclusion must be qualified, as the incremental effect of age-weighting will depend on the duration of disability. Barendregt *et al.* (1996) concede that given the rather small impact of the age-weight function on the specific life expectancies, their findings are not likely to upset the results of the GBD study.

Furthermore, Murray and Lopez (1996[b]) argue that one can debate the actual values incorporated into the DALY but that once each of the values has been chosen one should accept the consequences of the combination of these values in calculations.

4.3.2.2 Discounting

The discounting of health benefits is controversial. Bowie *et al.* (1997) lists three reasons why individuals are likely to value future health benefits less than present benefits, so making discounting important:

1. impatience or myopia - there is generally a preference for benefits now rather than in the future,
2. uncertainty that one may not be capable of receiving future benefits and
3. diminished marginal utility - one is likely to value additional units of benefits progressively less.

Anand and Hanson (1997) state that as with the case of age-weighting, a consistent defence of discounting could be provided if the human capital approach to valuing life were adopted. However, Murray rejects this framework.

One consequence of discounting life years is that “future generations become virtually valueless” (ibid P 91) and that prevention is devalued as costs are incurred now with benefits only years later. On the other hand, if costs are discounted and benefits are not similarly discounted then it follows that it will always seem to be more cost-effective to defer treatment. Discounting the health benefits as well as the costs avoids the so-called time paradox.

A further issue is whether both benefits and costs should be discounted at the same rate. Bowie *et al.* (1997) concludes the choice of discount rate is a policy issue and not just a technical question. It is interesting to note that the discount rate is more sensitive than age-weighting. According to Barendregt *et al.* (1996), the impact of discounting, even at the low value of 3%, as used in the GBD, is much larger than the age-weighting.

4.3.2.3 Disability Weights

Paalman *et al.* (1998) highlights a common criticism concerning the definition of the disability weights. They argue that there is a lack of transparency with the process whereby disability weights were established and apportioned among the different conditions in the DALY calculations. In addition, there are different dimensions used in defining the disability classes. The ability to pursue certain activities is used in some categories and the need for assistance used in others. These dimensions are not mutually exclusive. In order to be consistent all categories should have the same dimensions (Paalman *et al.* 1998).

Also, as the duration and the severity of a disability are separated in the calculation of the DALY, their interaction is not captured. For example, the difference in utility loss for an individual due to temporary or permanent functional impairment is not taken into account. One is not able to distinguish between an individual with a certain disability weighting lasting ten years or ten individuals having the same disability weighting with the duration of one year each (ibid).

Furthermore, Paalman *et al.* (ibid) contend that the disability weightings do not make allowance for conditions worse than death. Musgrove (2000) replies to this criticism by saying that these conditions are so rare and often short-lived so as to make little contribution to the overall burden of disease.

DALY disability weights are at present determined by a panel of experts. The participants in a study on rural Cambodian women recommended that more open, transparent and inclusive processes be used to develop disability weights particularly for the application of the DALY at local level (DALYs and Reproductive Health 1999). This serves as an example of how marginalised sub-populations can be included in health policy formulation. So if the DALY is to be used at the more local level for setting national or sub-national health priorities, then not only epidemiological experts should be consulted, but input from those suffering from a condition, their family, health care providers and the general public should also be considered (ibid). This partly answers the criticism that with the DALY the burden which falls on households and communities is not included. On the other hand, if the DALY is to be used primarily to generate global level assessments of the overall burden, the use of panels of experts, representative of different regions and specialisations is acceptable.

The recently conducted Netherlands (Melse *et al.* 2000) and Australian (Mathers *et al.* 1999) burden of disease studies have overcome the problem with the measurement of the disability component of the DALY by using empirical data to link health status with diseases. This addresses the issue of the definition of disability weights, at least at the country-specific level.

4.4 CO-MORBIDITY

Multi-pathology refers to the simultaneous co-existence of more than one disease in a given individual. Each condition with its disability weight could result in these weights adding up to more than one for a given individual. This suggests that co-morbidity is not permissible in DALY formulations (DALYs and Reproductive Health, WHO 1999).

Murray and Lopez (1997[a]) contend that the criticism that the multi-factorial nature of mortality and morbidity cannot be captured by the DALY is contentious. Diabetes mellitus

(DM) is given as an example to show that this has been done for some factors. Firstly, they estimated the burden of premature mortality and disability attributed directly to DM. Then they examined the total burden attributable to DM considering it as a risk factor for other conditions.

Sayers and Fliedner (1997) point out that multi-pathology is not the same as multi-causality. The latter refers to multiple risk factors involved in the occurrence of various individual diseases. Although multiple risk factors are undoubtedly involved in the occurrence of various individual diseases, the simultaneous co-existence of more than one disease in an individual is quite a different issue. The DALY does not take this into account. In effect, interventions are based on the underlying hypothesis of a single disease.

Risk factors are those variables that can significantly increase an individual's risk of developing the disease. The risk factors in the GBD are: tobacco use, unsafe sex, malnutrition, excessive alcohol intake, hypertension, physical inactivity, illicit drugs, air pollution and poor water supply, sanitation and personal and domestic hygiene practices. However, there may be equally important long-standing socio-economic factors such as poverty, inadequate housing and poor education. In addition, positive situations are not considered; such as a person being better able to cope with a disease or disability because of good social support, or perhaps the person is psychologically better able to deal with the illness. These long-standing factors are just as important as the other risk factors. The DALY is limited to the immediate determinants of disease or disability (ACHR 1995).

Although risk factors for disease receive attention in the GBD study, Murray (1994) acknowledges that co-morbidity requires further research. Murray and Lopez (1997[b]) also specifically note that there is a need to examine dependent and independent co-morbidity.

4.5 USE OF THE DALY FOR SETTING HEALTH RESEARCH PRIORITIES

The ACHR Review Group (1996 P 334) in their DALY critique strongly discounts the value of the DALY for setting research priorities as the following have not been adequately demonstrated:

1. verification of the methodology (that it does what it purports to do)

2. validation of the underlying concept (i.e. that the DALY provides a valid basis for decision making)
3. assessment of its utility in practice (in comparison with other methodologies)

The ACHR Review Group (ibid) has argued that the DALY methodology has not been validated and therefore it is not useful for health resource allocation. Murray and Lopez (1997[a]) answer this criticism by making three main points:

1. The mathematical formulation of the DALY has been thoroughly reviewed with no objections.
2. In order to counter the criticism that the social values incorporated into the DALY have not been validated, Murray and Lopez (ibid) conducted sensitivity analyses. These measured how results are affected by alternative values for the discount rates and age-weights. DALYs were calculated with a zero discount rate and uniform age-weights versus DALYs calculated with a 3% discount rate and non-uniform age-weights. Changing these important social preferences has little effect on the rank order of conditions. Sensitivity analysis is used in determining how much the result changes as a function of systematically varying one or more of the variables (Morrow and Bryant 1995). Anand and Hanson (1997) contend that although much has been made of the existence of sensitivity analyses concerning unequal age-weights, discount rates and disability class-weights, insensitivity to parameter changes can hardly validate a formula.

Anand and Hanson (ibid) further suggest that there is some evidence to support the possibility that individual diseases are sensitive in compensating directions resulting in a relative lack of overall sensitivity.

3. Finally, the Review Group (1996) argues that the epidemiological parameters (incidence, duration, prevalence and death) for each condition has not been validated. Murray and Lopez (1997[a]) make the point that uncertainty associated with epidemiological parameters has nothing to do with the validity of the DALY as a health outcome measures but has much to do with the validity of the results of the GBD study. They acknowledge that there is a need to improve data in order to narrow the range of uncertainty for estimates.

4.6 ISSUES OF EQUITY

According to Morrow and Bryant (1995) the WDR refers to the importance of equity and the principles and methods it espouses are equity-oriented. The report clearly states that the DALY approach would guide allocations towards the greatest burden of disease and the most cost-effective interventions. Generally speaking that guidance will be toward those in greatest need. According to Paalman *et al.* (1998 P 24), “the fact that the most efficient interventions identified in the WDR tend to specifically benefit the poor is more a result of coincidence than principle.”

Anand and Hanson (1996) elucidate that the very essence of public health is concern for equity which requires giving priority to the claims of disadvantaged people, not diseases. Murray (1994) argues that in terms of equity it is necessary to compare “like with like” and not to value death at a given age more in a high life expectancy country than in a low one. Murray and Lopez (1997 [a]) also defend the egalitarian framework on which the DALYs have been developed, stating that there is an ethical dimension of all health outcome measures. The DALY methodology explicitly states the underlying assumptions which may not be the case for other measures. “The normative aspects of a health indicator become evident when the measure is used as an aid to allocating health sector resources” (Murray and Lopez 1997[a] P 378). Furthermore, use of the DALY fosters constructive debate on the social choices that must be made to inform health resource allocation.

Janovsky and Cassels (1996) counters this by saying that the acknowledgement of assumptions does not negate the fact that they have been made. According to Anand and Hanson (1996) proponents of the DALY do not distinguish between the exercises of measuring the burden of disease and of allocating resources. The appropriate information sets for the two exercises are quite different. The DALY is used for the exercise of measuring the burden of disease and for resource allocation. However, the latter has ethical implications.

The ethical dimensions relate to the allocation of resources among individuals. Anand and Hanson (*ibid* P 688) pose the question: “What of those who are different along dimensions not included in the DALY information set?” In this regard the DALY fails to make

distinctions along dimensions such as income and socio-economic status which are important for allocating resources. "It is not ethical to treat similarly people of the same sex and disability status who differ in critical characteristics such as wealth or access to publicly provided services" (Anand and Hanson (ibid) P 701). According to them, the age-weighting and discounting schemes of the DALY have implications for resource allocation.

When allocating resources within the health system, the principles of cost-effectiveness and equity can result in conflicting recommendations. An example is the provision of health-care for remote and deprived populations in order to improve equity as opposed to providing care to more accessible populations which may be more cost-effective. Morrow and Bryant (1995) suggest that this conflict may be resolved by attributing infra-structural costs not only to the health sector. In addition, the gains in healthy life years will be greater in the under-served population than in those populations that have access to services.

4.7 GENDER

A critique of the DALY from a gender perspective clearly illustrates the impact of all the above-mentioned concerns. The critique is presented in terms of the previously discussed issues. In favour of DALY methodology when dealing with women's health and reproductive health, it is pointed out that the DALY is an advance on other quantification methods such as mortality indicators (DALYs and Reproductive Health WHO 1999). This is illustrated by the following example. For 1990 the average mortality rate due to pregnancy-related causes is 0,36% (585 000 cases) while the total figure for pregnancy-related complications is 12,5% (20 million cases), (DALYs and Reproductive Health 1998[b] P 4). These mortality estimates do not reflect the extent of ill-health associated with pregnancy as DALY calculations from the World Development Report estimate that reproductive ill-health accounts for 36% of the total disease burden among women of reproductive age (15-44 years) in developing countries compared to only 12% for men. If perinatal causes are added, some 13,5% of the total DALYs lost can be ascribed to reproductive ill-health (all ages and both sexes combined) (DALYs and Reproductive Health 1998[a] P 1). Although the DALY served to highlight reproductive health issues it also has its shortcomings in this arena. Many of the criticisms are the same as those generally levelled at the DALY.

4.7.1 CONCEPTUAL ISSUES WITH REGARD TO GENDER

One specific example which relates to value judgements inherent in the DALY concerns the inability of the DALY methodology to take into account the burden of ill-health associated with stillbirths. Stillbirths are an adverse outcome of pregnancy linked to inadequate health care during pregnancy and delivery and should be part of the burden of reproductive ill-health (DALYs and Reproductive health 1998[c] P 3). “By definition no individual can have any expectation of healthy life until the moment of live birth. Stillbirths are therefore not counted as adverse outcomes either for perinatal conditions or for the mother unless the stillbirth is associated with a maternal condition such as obstructed labour” (DALYs and Reproductive Health 1999 P 10). There are some fundamental flaws in a methodology that ascribes a loss of 33 DALYs to a newborn that dies within a few minutes after birth but nothing at all to an infant whose death occurs a few minutes before due to intra partum complications (DALYs and Reproductive Health 1998[c] P 3).

Two important conceptual issues are: What is being measured in terms of burden and who shoulders the burden. Anand and Hanson (1996) argue that the indicator appears to be more reflective of “quantity” of ill-health as opposed to “burden” of ill-health as is commonly understood. “The burden of a condition is in direct proportion to the assistance available to deal with it. What is a burden to a poor woman in a Third World slum is a mere passing inconvenience to her richer sister in New York” (DALYs and Reproductive Health 1998[b] and 1999 P 8).

The DALY measures the amount of ill-health but it excludes socio-economic, cultural and environmental factors which impact on burden as well as peoples’ differing abilities to cope with that burden (ibid). Reproductive health deals with both physiological processes and diseases which have unique cultural and socio-economic ramifications.

When considering aspects of women’s health such as menstruation which is a normal bodily function that is closely related to reproductive health, various cultural aspects come into play. For example, a menstruating woman in some countries cannot cook or pray or have intercourse with her husband. It is a real burden in terms of impeding daily life. These are not accounted for when using DALY methodology.

The theoretical underpinnings of the DALY have the effect of discriminating against the socially more vulnerable sections of the population. The DALY methodology is based on a decision to take account of disability rather than handicap (DALYs and Reproductive Health 1999).

The emphasis on disability and the exclusion of other variables such as socio-economic status, means that women's health is not being measured adequately. The ramifications of certain health conditions for women are unique and should not be ignored. A specific example is that of obstetric fistula: permanent incontinence as a result of obstetric fistula seems fairly straightforward in terms of disability. However, sequelae which can include social isolation resulting in divorce and abandonment are less likely to follow other disabling conditions (DALYs and Reproductive Health 1998[c] P 2). "Many conditions involve discomfort, pain, suffering, stigma, or social or economic consequences that are not explicitly incorporated into the DALY" (DALYs and Reproductive Health 1999 P 8). Another example is dyspareunia, which involves relatively minor physical damage but clearly inhibits the individual's right to "a satisfying and safe sex life" (DALYs and Reproductive Health 1998[b] P 10).

The DALY tool has also be questioned in terms of its application of a vertical, organ and disease structure for the classification of diseases, namely the International Classification of Diseases (ICD). The result is that "diseases are grouped together in terms of related pathologies rather than according to epidemiological patterns, determinants and consequences" (DALYs and Reproductive Health 1998[a] P 2). This approach tends to neglect the inter-connectedness of diseases and conditions related to sexuality and reproduction. Furthermore, it has been argued that the very identification of DALYs "implies that the diseases which most people suffer are identifiable, discrete conditions which can be tackled one by one" (Barker and Green 1996 P 181). A consequence of this approach is a failure to recognise the complexity of ill-health and of interventions. In mitigation of this criticism of the DALY, it is argued that there have been some attempts to group related diseases, for example the childhood illnesses, although this may not have been adequately done for women's health.

DALY calculations are based on the Japanese model which set a standard of 82.5 years for female life expectancy at birth. For males the comparable figure is 76 years. This implies a sex differential of about 6 years. In the DALY calculation the sex differential used is only 2.5 years; the rationale being that the wider differential is a function of male life styles and behaviours and will close overtime. However, if the true biological gap is greater than 2.5 years, this assumption leads to an underestimation of the burden of disease for women relative to that of men (Anand 1996, DALYs and Reproductive Health 1999). On the other hand, if the true biological gap is less than 2,5 years, then the burden of disease for women will be over-estimated relative to men.

4.7.2 TECHNICAL ISSUES WITH REGARD TO GENDER

“Women’s advocates have always pointed out that more health data are processed for men than for women.” In addition, where there are no gender dis-aggregations, the norm is often the adult male (DALYs and Reproductive Health 1999 P 26). A problem concerning the 1993 calculations of the global burden of reproductive ill-health relates to the databases which provided the foundation for the calculations themselves. The paucity of information on reproductive ill-health which is partly due to the difficulty of measuring gynaecological morbidity, inevitably leads to its neglect in the DALY calculations (DAL Ys and Reproductive Health 1999).

DALY calculations are biased towards maternal conditions and there is a relative neglect of other aspects of reproductive ill-health, exceptions being STDs and HIV/AIDS (ibid). The conditions which are excluded are closely related to women’s reproductive roles e.g. anaemia, osteoporosis, reproductive tract infections and sexual violence such as rape and sexual abuse with the associated mental health problems (DALYs and Reproductive Health 1998[b]). The focus on DALYs could limit the perception of women’s health to complications and diseases related to pregnancy. Broader social and economic issues are ignored e.g., teenage pregnancy (Stevens 1997 P 310). Domestic violence is not included as a reproductive health issue despite evidence that this violence may be related to women’s sexuality and reproduction.

There has been no systematic attempt to quantify the total burden of reproductive ill-health (DALYs and Reproductive Health 1998[a]). There is a vast menu for reproductive ill-health including not only reproductive issues but also sexual behaviours, sexually transmitted diseases, diseases of reproductive organs and certain cancers. Other issues also need to be considered such as female genital mutilation, sexual violence and associated mental illness (DALY and Reproductive Health 1998[b]). Some aspects of reproductive ill-health neglected in the 1990 GBD study should be considered for future health research priority setting. For example, DALY calculations do not take into account the side-effects of contraception. These may be negligible in terms of mortality or disability; however, discontinuation may well lead to an unwanted pregnancy (DALYs and Reproductive Health 1998[b]). It is suggested that sexuality and reproduction be incorporated into DALY calculations as a risk factor.

The DALY does not include acute events or health conditions with a short time base. Physical events such as abortion or miscarriage with the associated longer lasting psychological burden is not valued with the use of DALYs. In addition, much of the overall burden of reproductive ill-health occurs outside the reproductive ages e.g., prolapse or cervical cancers (DALYs and Reproductive Health 1999). The health of older menopausal women should be included in reproductive health.

A short-coming of the DALY, namely that of neglecting cumulative morbidity or the interdependence of diseases can be particularly problematic for women's health. A pre-existing condition, such as diabetes, a tropical disease or depression can be aggravated by pregnancy (ibid). Certain diseases that can affect everyone have particular manifestations among women, particularly during pregnancy. Examples include hypertension, cardiovascular disease, malaria and viral hepatitis. These can be indirect causes of maternal death. Even though they are not, strictly speaking, components of sexual or reproductive ill-health they can account for about 20% of total maternal mortality (DALYs and Reproductive Health 1998[b]). There are also some diseases that affect the reproductive tract that are particular manifestations of diseases that can affect anyone, e.g., genital schistosomiasis. The genital manifestation of the disease is thought to affect, at least intermittently, about 75% of women of child-bearing age in Africa who are infected by the parasite. Symptoms include inter-menstrual and post-coital bleeding, vulval and

vaginal tumours, ectopic pregnancy and infertility. In addition, some of these symptoms are mistaken for sexually transmitted diseases with consequent social disruption and mental anguish (ibid).

“A start on improving the current calculations could be possible with relatively limited investment of time or resources and even in the absence of a fundamental questioning of the whole approach. Information on, for example, female genital mutilation and violence against women should be built into the estimates as data become available” (ibid P 3).

The DALYs and Reproductive Health Reports in particular, have highlighted a number of technical and conceptual problems. As is the case with the general DALY critique, some of the technical, more practical problems can be improved with relatively simple modifications. However, the conceptual underpinnings with the concomitant value judgements and assumptions are not easily remedied (DALYs and Reproductive Health 1998[b]).

This gender critique has shown that value judgements are intrinsic to the DALY methodology. To reiterate: A transparent approach is needed to deal with criticisms of these value judgements, specifically in terms of what criteria are used as well as a reconsideration of the various assumptions (ibid).

4.8 POVERTY

Legge (1993) incorporates a critique of the DALY within a broader criticism of the WDR. According to him it is not self-evident that the economic health policies of the World Bank, based on the utilisation of the global burden of disease exercise, are entirely consistent with the health needs of the poor in developing countries (Legge 1993). He maintains that the consideration of health issues was constrained by a concern for economic objectives. Legge questions the significance of the Bank ignoring the contradictions between economic growth and health. Legge (1993) notes that the focus of the Bank's Report is on economic growth with the qualification that it should help the poor. The report skirts around relations between inequality and health. Rapid economic growth has in many countries been associated with the emergence of gross inequalities and widening health differentials

(Legge 1993 P 17). However, in the report there is no calling to redress inequalities in the distribution of income and wealth.

Legge (1993) casts aspersions on the intentions of the World Bank and its utilisation of the global burden of disease exercise. He maintains that the WBR ignores health and equity. Instead the focus is on health and poverty (UWC lecture 1996). Furthermore, the Report does not explicitly recognise that global interconnectedness can contribute to poor health in developing countries and that things like debt repayment from developing countries to the banking systems of the rich is not contributing to the health of the poor. Gwatkin and Heuveline (1997) go further than Legge and focus on the health needs of the poor. Criticisms of the GBD by Gwatkin and Heuveline (1997) incorporate issues such as the heterogeneity of the population, socio-economic factors as well as the issues of poverty and equity.

The important Alma-Ata conference of 1978 drew attention to the unacceptable health status of hundreds of millions of poor people, especially in developing countries. Gwatkin and Heuveline (1997) refer to three major reports produced in the 1990s in which a concern about poverty and equity are important, if not central issues. 1) The 1990 report of the CHRC entitled, Health Research Essential Link to Equity and Development. 2) The World Bank's 1993 World Development Report. 3) The Initiative for Health Research and Development for the Poor has been established to implement the recommendations of the 1996 Report of the WHO Ad Hoc Committee on Health Research Relating to Future Intervention Options (Global Health Forum).

They contend that the contents of these three reports profess a special concern for poverty but the policy recommendations are based on epidemiological analyses of population groups in which a majority of the people are not poor. In fact, the non-poor constitute a clear majority of the subject population since the poor represent no more than a third of the global population under any definition of poverty currently in widespread use.

While the focus of epidemiological analysis has shifted towards the population of the world as a whole, most global health policy statements emphasize the importance of improving the health of the global poor. Gwatkin and Guillot (2000) also refer to what they perceive to be a lack of congruity between the emphasis of the 1990 World Health Reports dealing

with poverty and equity and the underlying epidemiological analysis. They maintain that the world's poor cannot rely on the patterns of disease that reflect global averages for appropriate resource allocation (for prioritisation of health interventions and the health research agenda).

Gwatkin and Heuveline (1997) re-analysed the Murray-Lopez data for the one billion poorest 20% of the world population and for comparative purposes, the world's richest 20%. They found that while communicable diseases constituted only a minority of deaths in the world as a whole in 1990, they continued to cause the majority of deaths among the world's poor. The relative importance of communicable and non-communicable diseases in the poor group is almost exactly the reverse of that appearing in the overall global figures (ibid P 16).

TABLE 4 : Cause and Age Structure of Death among the Global Poorest and Richest 20%

Cause of Death

| Population Group | | | |
|---------------------------|---------------------------------------------|----------------------------------|---------------------------------------------|
| Disease Category | Poorest 20% of the Global Population | Global Population Average | Richest 20% of the Global Population |
| Communicable diseases | 56.1% | 32.8% | 8.4% |
| Non-communicable diseases | 33.6% | 55.7% | 84.8% |
| Injuries | 10.3% | 11.5% | 6.8% |
| Total | 100.0% | 100.0% | 100.0% |

Age at Death

| Population Group | | | |
|-------------------------|---------------------------------------------|----------------------------------|---------------------------------------------|
| Age Category | Poorest 20% of the Global Population | Global Population Average | Richest 20% of the Global Population |
| 0-14 | 47.4% | 29.9% | 4.8% |
| 15-59 | 25.7% | 24.2% | 19.2% |
| 60+ | 26.9% | 45.9% | 76.0% |
| Total | 100.0% | 100.0% | 100.0% |

Source: Gwatkin and Heuveline (1997)

To the extent that one wishes to set health policy priorities on the basis of burden of disease considerations they concluded that: 1) Among the global poorest 20%, communicable diseases at younger ages deserve highest priority but non-communicable conditions afflicting adults and the elderly cannot safely be ignored. 2) Among the global richest 20%, non-communicable diseases would be the primary overwhelmingly dominant priority. See Table 4 for the various percentages. Table 4 shows that when the health of the poor is analysed separately, the profile differs from the global population averages.

The ACHR (1996) also argue that the use of the DALY which is a measure of pooled data across heterogeneous populations results in distorted policy making and resource allocation. Murray (1996[a]) suggests that by describing burden in different socio-economic groups there is no need to build equity into the calculation of the burden. Furthermore, on a global scale the calculation of GBD using DALY has demonstrated large differences in the burden of disease between developed and underdeveloped countries and this should result in more equitable health research policy.

Sayers and Fliedner (1997) in their counter-reply state that regional heterogeneity is more complex than Murray and Lopez (1997[a]) imply. In order to take equity into account, various economic and social disparities across communities need to be considered. They suggest that to have a single numerical measure which must be disaggregated, is pointless. Paalman *et al.* (1998) also discusses the issue of population heterogeneity. The method of estimating the burden of disease fails to reveal whether a disease is concentrated in certain parts of the population. It is argued that most mortality and morbidity is concentrated in a minority of people. The identification of these individuals or groups is likely to lead to a different set of research priorities (Faechem 1989, Murray 1990).

Overall, the DALY is too focussed on the biological and genetic differences between men and women and there is a need to examine gender inequalities and their impact on health outcomes. The DALY, per se, is not a good tool for estimating the differential burden for a given condition that is carried by the poor. As the emphasis on equity in health increases, the burden of disease carried by the poor as well as gender inequalities in health cannot be ignored. Indicators worldwide suggest that there is a growing gap between poor and

rich within countries and across nations and that there is an increasing feminisation of poverty (DALYs and Reproductive Health 1999). Recent statistics of the United Nations Development Fund show that women are still the poorest of the world's poor representing 70% of the 1,3 billion people who live in absolute poverty (Cape Times, August 10, 2000 P 5).

4.9 USE OF THE DALY FOR RESOURCE ALLOCATION

4.9.1 COST-EFFECTIVENESS ANALYSIS (CEA)

Prioritisation for health research is part of the overall resource allocation for health. Cost-effectiveness studies of health interventions is an essential component for prioritisation and complement a DALY analysis. In strict economic terms the size of the burden is irrelevant as cost-effectiveness is only concerned with efficiency. According to Musgrove (2000), the emphasis in the WDR on the combination disease burden and cost-effectiveness constitutes its principal novelty.

The WDR uses the US\$ as common currency for measuring costs and the DALY is used as the unit for measuring outcomes or health effects. Different interventions can be compared by what it costs to achieve one additional year of healthy life. The ratio of cost and effect or the unit cost of a DALY is called the cost-effectiveness of the intervention; the lower the number the greater the value for money offered by the intervention. The aim is to maximize the DALYs averted per dollar. Assigning a monetary value facilitates decisions between intervention options. Priority ranking is given to those diseases which account for a large proportion of the burden and where there are cost effective interventions available. The WDR shows that large disease burdens can be controlled at relatively low costs (Musgrove 2000).

Although cost-effectiveness is central for establishing intervention priorities for the WDR, very little information is given on the 50 health interventions chosen and evaluated for cost-effectiveness which were obtained from another study (Paalman et al. 1998).

4.10 AVOIDABILITY

Bowie *et al.* (1997) list five features of the DALY formula which are contentious and require careful consideration from an economic theory and a public health viewpoint. Besides the use of age-weighting, the level of discounting, the weights used for disability and the method of calculating life-expectancy, Bowie includes the concept of avoidability. This concept is important when using the DALY to allocate resources.

Some components of the burden of disease in a community are impossible to do anything about and can be considered unavoidable. Others have been avoided but could return if intervention is withdrawn. Others are avoidable following the purchase of an appropriate health service intervention. The contribution of the unavoidable, avoided and avoidable components of the burden of disease need to be estimated (Investing in Health Research 1996). It is important to take note of the avoided burden when setting priorities so as not to withdraw support for those interventions which are already having an impact. The issue of avoidability is included as part of the systematic process used by the Ad Hoc Committee (1994) for setting health priorities. (See Figure 7 in Chapter 2.)

4.11 SYSTEMS ISSUES

The use of standardised life expectancies either in measuring the global burden of disease or in cost-effectiveness analysis implies that health interventions alone are capable of achieving an increase in life expectancy to these higher levels. Other socio-economic determinants in health, for example, increasing female education, improving water supplies and sanitation and reducing accidents and violence will also need to change in order for life expectancy to rise to the level used in the DALY calculations. Cost-effectiveness analysis in the DALY framework is a restrictive analysis for resource allocation as only the health sector is taken into account (Anand and Hanson (*ibid*)). However, in order to make comparisons involving other sectors, monetary values would have to be assigned to the outcomes and cost-benefit analysis applied which would be particularly difficult for comparisons across countries (Musgrove 2000).

In addition, within the medical model framework, the DALY has been criticised for failing to recognise links between diseases. There is also the assumption that one intervention can be considered largely in isolation from others (Save the Children Fund (SCF) 1993). Barker and Green (1996) maintain that cost-effectiveness techniques involving DALYs

result in a focus on vertical programmes. SCF (1993) suggest that the use of DALYs has no future as there is no recognition of the complexity of both ill-health and interventions. The use of cost-effectiveness methodology to allocate scarce resources for health interventions may lead to failure to build strong health systems capable of planning and implementation in a co-ordinated and integrated way.

Barker and Green (1996) further contend that the health-care packages based on the DALY are simplistic and do not take process into account. The problem with attempting to determine health sector priorities by defining priority health interventions is that health-care planning depends on priority setting beyond those of an epidemiological nature. Barker and Green (ibid P 181) also maintain that the approach is in the spirit of rational comprehensive planning and neglects the “existing legacy of health care provision, infrastructure and power relations”.

Barker and Green (1966), Sayers and Fliedner (1966), Anand and Hanson (1996) and DALYs and Reproductive Health (1998[a]) all refer to the use of the medical model of care, with the focus on disease and treatment outcome, as being problematic for resource allocation health.

4.12 CONCLUSION AND RECOMMENDATIONS

The detailed critique of the DALY shows the very complex nature of priority setting. It demonstrates how the very measure that is used to guide the priority setting process involves assumptions and values. Furthermore, it helps elucidate the issues involved in priority setting ranging from the technical to the conceptual and the ethical.

As can be ascertained from the preceding discussion, the proponents for the use of the DALY as a measure of burden of disease have gone some way to answer the various criticisms levelled at the measure. Work on the global burden of disease is on-going and it is constantly being updated, refined and improved.

Composite measures together with cost-effectiveness analysis considerably aids resource allocation and health research prioritisation. The prioritisation process is enhanced by an understanding of the limitations that are set and the consequences of the underlying assumptions of the health outcome measures used.

Priorities for health research derived from poor epidemiological and incorrect cost-effectiveness data will not be valid. It is necessary to improve economic analyses and 'evidence-based medicine' information. The DALY methodology can be improved by obtaining better data and more rigorous evaluation of available data.

Values incorporated in the DALY may be as important as technical debates (DALYs and Reproductive Health 1999). Barker and Green (1996 P 182) reject what they refer to as 'off the peg DALYs', calculated on the basis of someone else's data and incorporating their values. Barker and Green (1996) conclude that if DALYs have a future at all, they should be seen as indicators which must be developed locally on the basis of the judgements and priorities of local communities in the service of these communities. In the local context this will necessitate finding ways of measuring population-based values for an indigenous South African burden of disease study. (This relates to the health policy arena which cannot be ignored in the priority setting process). It is vital to incorporate community preferences as the criteria of equity and social justice for resource allocation are very important in the South African context.

It is important to note that the DALY methodology does not have equity built in. DALYs are valued the same no matter who gains them. "Valuing DALYs gained by disadvantaged groups higher would encourage measures to improve equity" (Paalman 1998 P 29).

On balance, there is a case for continuing research on composite indicators for purposes of describing health status. However, for research prioritisation there is a need for additional multi-disciplinary information.

Notwithstanding all the criticisms, it is recommended that a National Burden of Disease Study that estimates both mortality and non fatal outcomes for South Africa should be a top health research priority. In addition, the study needs to estimate the burden experienced by the poor. In South Africa, the Apartheid policies of the past have resulted in a strong correlation between race and wealth. Thus a national burden of disease study needs to estimate the burden by population group.

The DALY can be used as an adjunct tool for priority setting in the health and health research arena. The criticisms of the DALY such as those relating to the underlying values of equity, can also be addressed by using the DALY as a tool within a broader, priority-setting process such as ENHR. (This will be discussed in greater detail in Chapter 5). The DALY should be part of a systematic priority-setting programme. Cognisance must be taken of the limitations of the DALY that have been highlighted especially those relating to social preferences. In South Africa where the emphasis is on the development of a new, equitable health system, particular note must be taken of the criticisms of the DALY that relate to it not being conducive to the development of an integrated health system. In addition, in terms of priority-setting for interventions, it is important to bear in mind that the measures of cost-effectiveness may not be equitable and unhelpful when adjusting for the mis-allocations of the past in South Africa. When setting health research priorities the focus should be on the needs of the poor and other vulnerable groups. In terms of gender inequalities, the health research needs of rural women should be prioritised.

CHAPTER 5

PRIORITY SETTING FOR HEALTH RESEARCH IN SOUTH AFRICA

5.1 HEALTH RESEARCH PRIORITISATION IN SOUTH AFRICA

Any process designed to set priorities ... should not lose sight of the fundamental questions:

whose voices are heard,
whose views prevail and, thus,
whose health interests are
advanced?

(RESEARCH INTO ACTION 1997)

In South Africa there is extensive poverty and inequality and hence it is imperative that health research be used effectively to promote health equitably and rationally.

5.2 HEALTH RESEARCH EXPENDITURE IN SOUTH AFRICA

A good start for a review of health research prioritisation in South Africa would be the assessment of what health research is currently funded. Health receives the next largest allocation of the total ANC government expenditure after education. The major focus of re-prioritisation of expenditure in the health sector has been the expansion of access to primary health-care, particularly in under-served areas (Poverty and Inequality in South Africa 1998 P 11).

Greater government health expenditure on its own (at any level of income and education) does not necessarily translate into better health for the population (Jamison *et al.* 1995). South Africa spends relatively more on health than most other countries yet its health status is poor (Sunday Times 1997). A recent WHO publication ranks South Africa number 182 out of 191 Member States for health status, as measured by the DALE, relative to expenditure for 1999 (WHO 2000). South African expenditure on health is high compared to other middle-income countries. The World Bank describes South Africa as a Middle-income country. Middle-income countries refer to those with per capita income of US\$ 696- US\$ 8625 in 1994. In fact, South Africa with a health expenditure of 8,5% of GDP in 1990 approaches that of Established Market Economies of 9,2% (ibid).

The National Health Expenditure Review estimated in 1991/92 that only 1,1% of the total expenditure on health in South Africa was spent on research. By international standards this expenditure is low (Blecher and McIntyre 1995). The Third World Academy of Sciences recommends that 2% of Gross National Product (GNP) of developing countries is a necessary minimum investment in indigenous science and technology development with health research receiving 10% of that amount (Health Research: Essential Link to Equity in Development 1990). South Africa falls below this recommendation. In 1991/2 1,04% of GDP was spent on all research with only 6,9% devoted to health (Blecher and McIntyre 1995). By 1995/6, 0.9% of GDP, (R484,6 billion) was spent on all research and 14% of this was spent on health (Synthesis Report of the National Research and Technology Audit, DACST 1998). However, when an estimate of private sector business expenditure on health research is included in the calculation, this percentage is reduced to 11,5% (ibid), displaying a persistent shortfall.

In addition, government funding of medical research has declined in recent years (Mbewu 1996). Considering the scarce resources for health research it is surprising that there has not been an explicit process of prioritisation for health research at a national level.

There is little information regarding what areas of research are funded in South Africa and accurate data on expenditure is not available. An analysis of publication titles by South African authors for 1994 showed that 81% of published articles were on basic research or of a clinical nature (Harrison and Yach 1995). This limited method of auditing health research revealed a preponderance of biomedical research and dearth of public health research. The main explanation for the emphasis on biomedical research in South Africa is the apartheid-induced distortion of the health system. Priorities in health research were set for the minority in power at the expense of the majority. The discretionary interests of researchers determined research priorities (ENHR 1991[a]). Public health research, for example, with its intrinsic elements of equity were contrary to apartheid ideology. This experience clearly raises a further question of who prioritises for health research.

5.3 SETTING HEALTH RESEARCH PRIORITIES IN SOUTH AFRICA: ENHR

South Africa is undergoing major social transformation following the democratic elections in 1994. Health has been placed high on the political agenda by the new government and universal access to primary health-care has become an important goal (A National Health Plan for South Africa 1994). Research in general was given added importance in 1994 through the establishment of a separate Ministry to manage science and technology. The new science policy endeavours to ensure that research will precipitate innovation and thereby promote social and economic development (White Paper on Science and Technology 1996). Applied research, is crucial to South Africa at this time (ENHR 1991[a]). The necessity for health research prioritisation was acknowledged with the adoption of the ENHR plan. ENHR is an internationally accepted philosophical framework for the promotion of health and development. ENHR is a complete integrated system that can be used for priority setting as opposed to piecemeal research efforts. An important ENHR strategy is to create a dynamic process linking policy, action and research thereby ensuring that research funding will be promptly and efficiently applied in health programmes. ENHR operationalises the concepts of equity and social justice “by advocating a national consultative process for priority setting and identifying people and organisations to implement decisions reached by consensus” (National Research and Technology Foresight Project 1999). The Ministry of Health has recommended that ENHR be adopted, endorsing it as part of the reform process (White Paper for the Transformation of the Health System in South Africa 1997). The values of equity and development in ENHR are clearly important criteria for the prioritisation process in South Africa. Community participation has been highlighted throughout this study as an indispensable part of setting local priorities. “In developed countries, the task of priority setting is being approached by combining analysis and research evidence with public consultation and debate, leading to the development of guidelines or protocols on priorities” (Ham 1994). The ENHR process allows for community participation in the setting of national research priorities.

The adoption of ENHR in South Africa began in 1991. In 1993 five representatives of organisations involved in community-based research attended the Geneva conference on

ENHR. Early in 1994 in support of ANC policy, the MRC and the alliance of progressive health NGOs also endorsed ENHR.

There has been much progress in the adoption of ENHR in South Africa. In 1995 the new Department of Health organised a national meeting of stakeholders in health research to plan the implementation of ENHR. Arising from this, a National Technical Committee was appointed to advise the Minister of Health on how to facilitate the implementation of ENHR. The National Technical Committee for ENHR Report followed an initial workshop and together with recommendations from a second workshop, led to the Chapter on Health Research in the White Paper for the Transformation of the Health System in South Africa (ibid). It is acknowledged in the White Paper that research has previously not been used to develop the health system and that there has not been a national research strategy. The establishment of a functional ENHR co-ordinating committee is recommended as a means to facilitate the implementation of this policy.

In addition, recommendations which emerged from the combination of the committee report and the national workshop held early in 1996 were handed to the newly created office of the Chief Directorate of Health Information, Evaluation and Research (HIE&R) in the Department of Health. (Neufeld 1996). After further consultation with stakeholders, there was a consensus that prioritisation of health research was a necessary step towards implementing the ENHR strategy. According to the ENHR National Technical Committee Report (1995), the consultative processes initiated by the committees and workshops were useful for motivating a general macro shift in priorities for research and identifying individuals and institutions to carry out research. However, the process failed to yield usable lists of specific research projects to be carried out at various levels of government (ibid).

In September 1996 a working group was established to assist in the development of the criteria and processes of prioritisation. Using the approach of the Ad Hoc Committee as a model, the first South African ENHR conference on priority setting was held in November 1996. There were 95 organisations identified as stakeholders in the ENHR process and the conference was attended by more than 160 participants representing 77 organisations (Proceedings of the First Essential National Health Research Congress on Priority Setting.

1996). These included representatives of universities, science councils, NGOs, international funding agencies, national and provincial health departments, government departments and the private sector. Local government was not represented and there was insufficient community representation.

The conference on prioritisation was structured as a stepwise process over a two-day period. Step one involved the ranking of health problems. An assessment of health status and trends based on available mortality and morbidity data was presented to the participants. Perceptions were included in the process through extensive group discussions. The major health problems were identified and then ranked using a vote. The top ten health problems are shown in Table 5.

Table 5: Top ten health problems identified by the 1996 Congress

| CONDITION | Congress Rank |
|-----------------------|----------------------|
| INJURY (all causes) | 1 |
| TB | 2 |
| NUTRITION | 3 |
| HIV/AIDS | 4 |
| STDs | 5 |
| CANCER | 6 |
| DIARRHOEA | 7 |
| RESPIRATORY INFECTION | 8 |
| MENTAL HEALTH | 9 |
| MALARIA | 10 |

Source: South African ENHR Congress 1996

In step two, groups discussed the top ten health problems separately and attempted to identify broad research areas required to address these problems. The participants assessed why the problems persist and what could or should be researched. These broad research areas were categorised by discipline. In the third step, cross-cutting issues, within four types of research, viz. basic, clinical, social science and health systems were discussed. These steps were generally undertaken with limited data and relied on the

expert knowledge of the participants. A preliminary list of research priorities as well as other ENHR concerns was generated within each research type and have been documented in the report (ibid). The Congress participants recommended that the list be considered as a basis for more substantive input from appropriate experts.

To date, slow progress has been made with the newly established ENHR Committee in facilitating the finalisation of the priority research list and the constituting of an ENHR mechanism. Although initially ENHR was warmly embraced by the relevant stakeholders such as the Department of Health and the Medical Research Council, the ENHR initiative seems to have lost momentum. There may not yet be consensus on the way the ENHR mechanism works.

The global and South African initiatives for setting health priorities have both used a combination of a health problem and health system approach. It would be premature to compare the list of research priorities identified at the South African ENHR conference with the global list until there has been further analysis and input.

However, the major health challenges identified in South Africa have been contrasted with the global list. In order to do so, the health problems and research priorities identified during the South African ENHR conference were studied in conjunction with the pre-conference submissions (ibid). Using similar groupings to those utilised in the Ad Hoc report and summarised in Table 6 , (Groenewald 1996) the major health challenges for South Africa are summarised in Table 7 (Schneider and Bradshaw, (2000, draft)).

Table 6: Summary of major health challenges identified by the WHO Ad Hoc Committee on health research relating to future intervention

| | Broad health challenges | Disease cluster | Specific disease/problem areas |
|---|------------------------------------------------------------------------------------------------------------------|--------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1 | The unfinished agenda | Childhood infections | Pneumonia Diarrhoeal disease Vaccine-preventable infections Malaria Helminth infestations |
| | | Malnutrition | |
| | | Poor reproductive health | Excess fertility/unwanted pregnancies Maternal and perinatal complications |
| 2 | Evolving microbial threats | | Tuberculosis Pneumococcal disease Malaria STDs including HIV/AIDS |
| 3 | Non-communicable diseases and injuries | Major non-communicable disease | Psychiatric and neurological conditions Cardiovascular disease Cancers Non-communicable respiratory disease |
| | | Risk factors for non-communicable diseases | Tobacco use Alcohol abuse Other (hypertension, inactivity, air pollution) |
| | | Unintentional injuries | Road traffic accidents Other unintentional injuries (burns, fires, poisoning) Risk factors for intentional injuries (alcohol) |
| | | Intentional injuries | Criminal homicides War-related injuries Risk factors for intentional injuries |
| 4 | Inefficient and inequitable health systems facing spiraling costs and lack of information to guide policy | | Interaction between health and economy Potential benefits of interventions in other sectors Impact of health sector reform Current and projected trends in health status Demand for services at population and household level Indicators of need Effective indicators of health system performance Priority setting for resource allocation |

Source: Groenewald 1996

Table 7: Major health challenges identified at the South African ENHR Congress 1996

| Broad challenge | Problem cluster | Specific problem |
|--------------------------------------|--------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1. Injuries and violence | Intentional injuries | Domestic and interpersonal violence Child and Women abuse |
| | Unintentional injuries | Road traffic injuries Occupational injuries Poisoning (domestic and agricultural) |
| 2. Evolving microbial threats | Infectious diseases | TB HIV/AIDS STDs Malaria Pneumonia Hepatitis |
| 3. The unfinished agenda | Malnutrition | Undernourishment Micro-nutrient deficiency Anaemia |
| | Poor child health | Diarrhoea Measles Perinatal mortality Parasitic disease Breast-feeding |
| | Poor reproductive health | Teenage pregnancy Unwanted pregnancy Maternal mortality and morbidity Infertility |
| 4. Non-communicable diseases | Major non-communicable diseases | Cancers Mental health (depression, post traumatic stress disorder (PTSD), anxiety) Non-communicable respiratory diseases (asthma, chronic obstructive pulmonary disorder (COPD)) Oral health |
| | Chronic diseases of lifestyle | Cardiovascular diseases (stroke, IHD) Diabetes Hypertension |
| | Risk factors for non-communicable diseases | Smoking Alcohol abuse Substance abuse |
| | Ageing | Senility Arthritis Osteoporosis |
| | Disability | Physical disability Mental disability |

Table 7 continue/...

| Broad challenge | Problem cluster | Specific problem |
|------------------------------------------------------|----------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 5. Inefficient and inequitable health systems | Restructuring health care | Health service financing Economic analyses of policy and programmes Methods for evaluation and monitoring Criteria for allocation of resources Community participation in health service provision Inter-sectoral collaboration |
| | Health Information Systems | Methods to monitor quality of services Poor surveillance systems Current and projected trends in health status |
| 6. Health and Development | Poverty | Lack of water and sanitation Lack/inadequate housing Rapid urbanisation Impact of inequality on health |
| | Environmental health | Air pollution, water pollution and solid waste |
| | Occupational health | Asbestosis Other occupational diseases |

Source: Schneider and Bradshaw (2000, draft)

It is interesting to note that the broadly defined areas of health research prioritisation for South Africa and globally for developing countries are very similar. The most notable differences are the problems of injuries and violence which are placed in a separate category as a result of the high ranking accorded to these problems. Globally, injuries are part of the non-communicable disease group. For non-communicable diseases, ageing and disability are identified as specific problems in South Africa. Health-care restructuring and health information systems have been targeted as the main problem clusters for inefficient and inequitable health systems locally. Health and development is a major health challenge that was identified in the South African process but is not part of the global list. This category highlights the inter-relatedness of health to the provision of water, sanitation, housing, pollution and other social issues such as rapid urbanisation. It also shows the impact of inequality on health and reflects the development focus of the new government.

A fundamental difference between the South African exercise of setting research priorities and that of the Ad Hoc Committee was the very rapid approach used in the case of South Africa. The Congress was a short-term, small scale exercise. The Ad Hoc Committee used extensive quantification of disease burden on a global scale with projections for the year 2020. The report of the Ad Hoc Committee was the result of a process that took two years with technical support provided by the WHO and the Harvard Burden of Disease Unit. In addition, data were generated on the relative cost-effectiveness of different interventions intended to reduce the burden of disease. The South African process relied less on such quantified information. The very rapid approach may have been compromised because of lack of data but it allowed the perceptions of the participants to play an important role in determining the top ranking of the health problems. The lack of community input also has a negative impact on the validity of the top ten problems identified at the Congress. In addition, while a broad overview of health status was presented, there was no information regarding the health system included at the South African conference. The challenge of inefficient and inequitable health systems is not dealt with adequately. In this respect, it would be useful to study how other developing countries have used ENHR for equitable development.

Another factor which affected the validity of the rankings identified by the 1996 South African Congress was the lack of information on the future burden, in particular AIDS. At the first ENHR Congress AIDS was only ranked fourth. Subsequently however, with better information, AIDS has become a top priority for health research. "When disease or risk factors change rapidly, the present burden is not a good indicator of the priority for their control" (Bobadilla et al. 1994 P 173). For emerging new diseases the expected future burden provides better input for priority setting.

5.4 NATIONAL RESEARCH AND TECHNOLOGY FORESIGHT PROJECT

The National Research and Technology Foresight Project is an initiative by DACST "as part of its mandate to review and reform the Science and Technology system in South Africa" (National Research and Technology Foresight Project 1999 P 3). The Foresight exercise is a comprehensive one covering twelve major sectors. These include health, mining, business, agriculture, information and communication technologies. The mission statement

of the Foresight project on health is to prioritise research and technology strategies in the health sector in order to promote sustainable development in South Africa (ibid).

A Foresight project is inherently pro-active and reflects the belief that the future is influenced by today's decisions and actions. The emphasis in the Foresight exercise is not prediction but the exploration of different scenarios. Constructing these scenarios helps assess how well current research and technology might address future socio-economic needs, that is, in the next ten to twenty years.

DACST began the South African Foresight exercise in July 1996. The report was published in 1999 with the recommendation that it be repeated within five years. A distinguishing feature of South Africa's Foresight exercise is that it involved a very wide range of stakeholders with contributions from industry, labour and civil society. The methodological approach included, in addition to scenario analysis, a survey of opinions on research and technology trends as well as a strengths, weaknesses, opportunities and threats (SWOT) analysis. The latter is a situational analysis of the internal and external environment of the South African health sector. In a SWOT analysis, opportunities and threats are considered to originate in the external environment and strengths and weaknesses are internal, originating within an organisation or structure.

The top research and development issues collated by the Foresight project are shown in Table 8. The development of an effective HIV/AIDS vaccine heads this list of specific projects for priority health research.

Table 8: Foresight priorities

| FORESIGHT TOP RESEARCH AND DEVELOPMENT ISSUES |
|---------------------------------------------------------------------|
| Development of an AIDS vaccine |
| Development of barriers methods/microbicides for STDs/HIV |
| Development of new TB drugs and a vaccine |
| Development of malaria drugs and a vaccine |
| Food fortification |
| Injuries and violence prevention |
| Health promotion targeted at the youth |
| Safer fertility regulation (male and female) |
| Self-management tools for chronic diseases and rehabilitation |
| Novel way of developing private/public partnerships for health care |
| Cost-effective on site diagnosis |
| Telemedicine |
| South African CDC |
| Health and safety assessment techniques |
| National Health Information System |
| Use of smart cards |
| Commercial application of indigenous knowledge |
| Research into effectiveness of alternative therapies |
| Tissue regeneration and gene therapy |
| Rational drug design |

Source: The National Research and Technology Foresight Project: Executive Summary. Health

The context for informed decision-making is enhanced by dialogue involving all relevant stakeholders. This “emphasises the human abilities of forethought, creativity, systems thinking, analysis and judgement ” (The National Research and Technology Foresight Project 1999 P 3). The application of these abilities are vital for determining appropriate national health research priorities.

5.5 MEDICAL RESEARCH COUNCIL PRIORITY SETTING

The MRC is one of eight science councils in South Africa. In 1999 the MRC received 6% of the Government's allocation to science. However, the international norm for a committed science allocation is 25% (MBewu and Mngomezulu 1999). There has been an increase in the MRC funding in order to address the major national health problems. DACST has approved a recommendation that the MRC's baseline budget be doubled over the medium-term with funding estimated at R176,1million for 2000/2001 (MRC 1999-2000).

The MRC does not have a list of research priorities nor does it report the level of funding allocated to different health problems. It is currently in the process of developing a more transparent mechanism for ascertaining, ranking and funding priorities for research. A consultative workshop was held in May 2000 with a small group of MRC and university researchers, managers and Board members together with representation from the Department of Health (DoH) to consider the process of priority setting for the MRC.

At the workshop it was recommended that health research priorities for the MRC should be developed from the ENHR Congress, Foresight project and its own Thrust process with consultation within the six new National Programmes. The aim of the consultation should be to identify the specific types of research. (The MRC Thrust process was an earlier restructuring process which involved extensive consultation within 20 areas of research (MRC Update '98).) Furthermore there is a need for an audit of MRC research funding according to the specific problem area and type of research in order to ascertain detailed research expenditure and identify under-resourced priority research. It is suggested that the pro-active mechanism of 'requests for proposals' be reintroduced to address priority areas that are under-funded.

5.6 THE HEALTH SYSTEMS TRUST (HST) RESEARCH PRIORITY SETTING

The HST is a non-governmental organisation that has become a recognised funder of policy relevant health systems research. The new health systems research agenda reflects a shift from policy formulation to the mechanics of implementation. This agenda has seven themes, each defining broad areas of research as shown in Table 9. Furthermore, it is envisaged that these broad research frameworks will serve to incorporate researcher initiated projects, addressing issues of national, provincial and district significance.

Table 9: HST priorities

| |
|------------------------------------------|
| HST RESEARCH THEMES |
| QUALITY OF CARE |
| REPRODUCTIVE HEALTH |
| DECENTRALISATION |
| HUMAN RESOURCES |
| HEALTH INFORMATION |
| HEALTH CARE FINANCING AND EXPENDITURE |
| PRIVATE SECTOR |
| PHARMACEUTICAL SERVICES |

Source: Health Systems Trust Research Programme 1999-2001

Each theme has examples of research issues that could be included. Some themes have sub-sections, for example, HIV/AIDS/STDs are included in the Reproductive Health theme. These research themes are valuable for health research prioritisation as priorities are presented from a health system perspective. In terms of Janovsky and Cassel's model (1996) the focus is on the mediating organisations and the supply side rather than the demand side.

5.7 THE SOUTH AFRICAN RESEARCH RESPONSE TO THE AIDS PANDEMIC

AIDS is a unique disease in terms of the extent of human suffering it causes; it also has the potential to radically alter the future demographic profile of South Africa. Furthermore, AIDS will be a major problem when attempting to reduce poverty and socio-economic inequality. It is a priority among priorities and consequently the setting of priorities for AIDS research has been fast-tracked.

The fight against AIDS is two-pronged, one arm is prevention, the other is treatment, as well as care and support for those infected with HIV/AIDS and others affected such as AIDS orphans. AIDS research must address both these areas.

A prominent thrust for AIDS research in South Africa is finding an effective vaccine. "Never in history has a viral disease been controlled by drugs. That's why a vaccine is the only

possible way to fight HIV”, Dr Walter Prozesky, SA Aids Vaccine Initiative (SAAVI) Co-ordinator (AIDS Bulletin, December 1999). In 1999 the South African Cabinet approved over R220 million over seven years for the SAAVI. The Medical Research Council concluded an agreement with the European Union for another R11 million grant for research into developing a model for preparing the population for HIV/AIDS vaccination trials (ibid). The SAAVI is supported by the International AIDS Vaccine Initiative (IAVI) which is investing US\$ 9.1 million in a mighty international effort to develop a preventative AIDS vaccine (MRC News, Sept 1999). Furthermore, the Government has ear-marked R500 million from the 2000 Budget for combating AIDS (Health Link Bulletin 2000).

A priority recommendation for AIDS research concerns obtaining data. Data for use in AIDS models for accurate projections are vital. The variables needed to model the AIDS epidemic include: the baseline rates of infection, behavioural risk factors, efficacy of transmission, incubation periods, survival times and the role of factors such as STDs which are not well quantified (WDR 1996). In South Africa data is needed in order to improve the application of the projection models of the epidemic. The required data include the timeous publication of national mortality data and more details concerning the antenatal clinic HIV prevalence figures (Dorrington 1999).

Other AIDS research areas need to be prioritised. These include, anti-retro viral therapies, AZT to pregnant women, mother to child transmission, the role of breast-feeding, monitoring intravenous drug usage and research into microbiscides. All these are in addition to the South African involvement as part of a global initiative to carry out AIDS vaccine trials.

There is the fear that the millions set aside now will continue to be squandered on AIDS awareness campaigns that, in the past, have not resulted in significant behavioural changes. In order for any initiative to be effective, the socio-economic dynamics of the AIDS epidemic need to be addressed (Health Link Bulletin 2000). In addition, it has been pointed out that it is useless allocating large sums of money when there is no capacity to implement AIDS prevention strategies (AIDS Bulletin 2000). Hence, it is important that the priority list includes research that aids the development of capacity for implementation and evaluation of the research priorities.

The political will to fight the AIDS epidemic has been shown to be an important factor in combating HIV/AIDS. However, public awareness and consensus are necessary to achieve political will in a democracy. This necessitates research on community participation in the battle against AIDS.

5.8 CONCLUSIONS

The World Bank's 1993 WDR has highlighted the fact that the health of the nation and sustainable economic growth are interdependent. Notwithstanding, the high political profile of the health sector in South Africa and despite the poverty, inequality and general scarcity of resources, only broad health research areas have been identified. Specific, prioritised health research topics have not been clearly identified.

There has been a protracted adoption of ENHR formulated in various policy documents with slow follow-through. The South African ENHR Conference which took place towards the end of 1996 developed a list of health challenges which are similar to those identified in the Global Burden of Disease Study. However, specific research questions need to be identified. The ENHR Committee has recently been constituted and it is hoped that priority setting for health research will receive precedence in the ENHR process.

There are various accordant priority lists of health research issues and health problems and challenges. These include: the Foresight Project, the ENHR Congress, the evolving list of the MRC and the HST research themes. The list of specific priorities determined by the Foresight exercise are important as they have a comprehensive base, namely identifying priority health and development research that contribute to 'wealth creation' and the 'improvement of the quality of life' for the people of South Africa. In addition, the goal is to help ensure that the country is economically competitive on a global scale in the long term. The MRC has gone some way to implementing the Science, Engineering and Technology Institute (SETI) Review's recommendation, namely that it should restructure its resources to increase alignment with ENHR priorities. The HST have defined the important research themes with corresponding examples of possible specific research issues. These latter issues have not been decided upon.

The analysis of available health research expenditure information shows that there has been insufficient monitoring of expenditure by health research type. There is no detailed information about current areas of research coupled with expenditure breakdowns.

AIDS as a priority among priorities has received attention for deciding specific health research priorities. Research priority setting for AIDS has gained its own momentum outside the broader health research prioritisation process. This is the result of the enormity of the AIDS epidemic in South Africa. However, to date, the focus of the AIDS research has been on bio-medical research such as seeking an AIDS vaccine, with the relative neglect of behavioural, public health orientated AIDS research. There is no transparent, systematic process that is followed in order to determine the specific priorities for AIDS. The AIDS research and funding has not been examined taking other health research priorities into consideration in order to prioritise across research areas.

CHAPTER 6

CONCLUSIONS, RECOMMENDATIONS AND FUTURE DIRECTIONS FOR HEALTH RESEARCH PRIORITY SETTING IN SOUTH AFRICA

6.1 CONCLUSIONS

Health research not only leads to improved health but serves to boost socio-economic development. Accompanying globalisation, scientific advances and the revolution in information and communication technology there are growing disparities in health and wealth both between and within countries. In response to these global trends socio-economic and gender equity should be central to the prioritising process for health research.

In South Africa, as in the rest of the world, there is concern about the optimal allocation of scarce health research resources. In the past, financial support for health research was mainly provided for clinical and laboratory research with the emphasis on highly technical medical advances. The bulk of public research funding went to biomedical research while other important areas of health research were neglected. These neglected areas included health policy, health information systems, health education and promotion as well as the relationship between developmental policy and health.

Overall, there is little evidence of explicit prioritisation for health research. Currently, there is insufficient detail concerning the exact magnitude and the manner in which health research funds are spent in South Africa. There is a need for greater clarity on how research is prioritised and funded. A full health research audit is proposed as the first step of the health prioritisation process in South Africa.

While the Global Burden of Disease (GBD) is overwhelmingly in the Third World, investment in health research focuses mainly on the health problems of industrialised countries. In response to these distortions in global health research prioritisation, the Commission for Health Research and Development has recommended that no matter how poor a developing country is, the establishment and growth of an appropriate health research base is essential. The Commission called this base, ENHR. The ENHR strategy as a guiding philosophy fits into the broader political climate prevailing in South Africa,

namely, the democratisation of the political process and a shift to social justice. The ENHR plan will focus South African research resources on the priority health needs of the entire population especially the poor.

Prioritisation is an integral part of planning and both, developed and developing countries need to determine health research priorities. This can be done from a health problem or a systems approach. Either way, prioritisation is a complex procedure that can be tackled in a systematic, step-wise manner. This approach will include the consideration of factors such as technical feasibility, availability of various resources and capacity, as well as sustainability of proposed health research.

Prioritisation is a political process that cannot be resolved by purely technical and scientific means but involves dialogue and debate as well as an underlying value system. Prioritisation relies on the less quantifiable aspects of peoples' perceptions and needs. In acknowledging the political nature of prioritisation, there is concomitant recognition of the different interest groups in society based on variables such as gender, education, religion and socio-economic class that in turn relate to individuals' values. Health research should be based on common underlying values.

Prioritisation involves a weighting of values. Ham (1995 [b]) states that it would be useful to define specific values which different stakeholders consider to be important. A number of values can be identified that can guide decision-making and usually include: effectiveness, efficiency, impact, equity and prevention. Health research should involve all stakeholders including civil society, at all levels. To this end, partnerships should be developed at local, national, regional and global levels.

There are various scientific techniques and epidemiological methods that can be used to manage health data and so help transform general health policy goals into specific objectives pursued by various stakeholders. Different approaches and priority-setting mechanisms will result in different priority lists. It is important to bear in mind that methods used to assist decisions on priorities may mask value judgements.

There has been extensive development of measures of health outcomes in the last decade. These include summary measures such as the DFLE and the DALE as well as measures of the health gap such as the QALY and the DALY.

An important focus in this thesis is an analysis of the contribution of the DALY to determining health research priorities. It is concluded that in addition to the mortality component, the DALY provides unique and desirable health information on non-fatal health outcomes that is essential for determining appropriate health research priorities.

A review of the ongoing debate about the DALY shows that there is still some need to refine the DALY as a measure of burden but more importantly that it is necessary to incorporate local preferences into the measure and to note that a national estimate of the burden would not identify the needs of the poor.

The health research priority-setting process in South Africa should be goal orientated and guided by the analysis of health status, burden of disease and developmental needs.

South Africa has gone a long way in identifying national health research priorities. A process of consultation and a workshop of stakeholders has resulted in the identification of the major health challenges (see Table 7, Chapter 5). These problems have been ranked at a national ENHR conference. However, the top priority problems remain to be analysed in more depth so that a specific health research agenda can emerge. The results of the South African priority setting Congress should be used judiciously. It is important that experts in the different areas be brought together to develop the research agenda within each of the six delineated problem areas. It is essential that the analyses of the Ad Hoc Committee be brought to bear on this process so that South Africa can benefit from the extensive work that has already been done.

The first four broad challenges listed in Table 7¹ have arisen using a health problem perspective and need further analysis along the lines of the five steps used by the Ad Hoc Committee. This requires more economic analysis and quantification than was available

¹Injuries and violence, evolving microbial threats, the unfinished agenda, non-communicable diseases

to the 1996 ENHR Conference. The information contained in the 1993 World Development Report and the Ad Hoc Committee Report (Investing in Health Research and Development 1996) will provide a good basis for these analyses. In addition, the work of the Cochrane Collaboration Centre at the MRC to assess the effectiveness of health interventions through systematic review would be useful. Further analysis of available data needs to be undertaken to estimate the national burden of disease in South Africa and identify whether there are subgroups of the population suffering a disproportionate burden.

The last two broad challenges from Table 7² have arisen from a health systems/policy approach and require a process similar to that suggested by Janovsky and Cassels (1996) to refine research priorities. This process needs to seek input from a wide range of experts and community than currently achieved as well as a more substantive situational analysis of the health-care system (Tollman 1997).

6.2 RECOMMENDATIONS FOR RESEARCH PRIORITISATION

A balance of priorities across these six broad challenges needs to be established. Identifying the priorities in health research will provide a map to guide the various stakeholders to determine what health research is ultimately carried out. However, prioritisation, considered in isolation from the other elements of ENHR, is unlikely to result in meaningful reform of the health research agenda. This will only be achieved if an ENHR Committee is established that has the capacity to drive the seven elements of ENHR. There are many obstacles that can undermine the implementation of ENHR (How to Boost the Impact of Country Mechanisms to Support ENHR 1999). The ENHR mechanism can become bogged down in bureaucracy, politicians may resist scrutiny of health outcomes and academic interests may override the primary objective of ENHR research: equity in health. The ENHR Committee should provide the leadership and common vision that health research be aligned with the priorities of the country. It will need to have the political backing through clear linkages with the various ministries that will help integrate ENHR plans into national social development plans. Key role-players need to be mobilised and help define health research policy. The ENHR Committee must be flexible in its operation, building on what already exists and where necessary, being innovative. Part of the process

²Inefficient and inequitable health systems, health and development

of sustaining the ENHR mechanism is to ensure that the traditional division between research and action is not perpetuated. Not only is institution and individual capacity development through the supply of resources and technical experts, required for the sustainability of the ENHR mechanism, but there should be an equal focus on strategies that generate a demand for research. There is a need to interact with the users of research.

Table 10 shows a sequence of steps for research priority setting in South Africa. In Table 10 the first step is that the ENHR Committee become operational and co-ordinate an ENHR strategy. Part of this is an evaluation mechanism for auditing expenditure and research in the country. The important part of the recommendations shown in Table 10 for prioritisation is the establishment of expert panels to identify and prioritise health research in a systematic manner. This needs to follow the 5 steps in the case of the health system approach or the 3 steps in the case of the systems approach.

Table 10: Recommendations for setting priorities in South Africa

| STEP | ACTION |
|------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1 | <p>Establish ENHR Committee</p> <p>Drive the seven elements of ENHR: promotion and advocacy, ENHR mechanism, priority setting, capacity development and strengthening, networking, financing, evaluation</p> |
| 2 | <p>Set up expert panels to identify and prioritise specific questions for each broad challenge*</p> <p>Categorise by research type</p> <p>*Health problem approach for the first 4 broad challenges:</p> <p>Step 1 - calculate the burden attributable to the disease</p> <p>Step 2 - identify the reasons why the disease burden persists mainly because:</p> <ul style="list-style-type: none"> a) a lack of knowledge about the disease and its determinants; b) lack of tools; c) failure to use existing tools efficiently. <p>Step 3 - ascertain whether the knowledge base is adequate to consider the development of new interventions. If not, more strategic research is necessary.</p> <p>Step 4 - will the desired intervention be cost-effective?</p> <p>Step 5 - assess the current level of outlay for Research and Development on the particular problem</p> <p>*Health systems and policy approach for the last 2 broad challenges:</p> <p>Step 1 - assess the perceived importance of the topic, either in terms of impact on health status or in relation to policy objectives such as efficiency or equity.</p> <p>Step 2 - will proposed research advance the current state of knowledge</p> <p>Step 3 - research methods must yield information that it is useful to policy makers</p> |
| 3 | <p>Establish mechanism for evaluation</p> <p>Review expenditure and nature of research on priorities (part of ENHR).</p> |

*See Table 7

The purpose of the above framework is not to generate a priority health research list per se but rather the development of a holistic, transparent system for setting health research priorities.

Notwithstanding the criticisms of the DALY as a measure of health outcome, it is recommended that the national burden of disease study proceed. In particular, the use of the DALY for Sub-Saharan Africa (SSA) has been criticised for its poor quality of health status data. However, one cannot await perfect health status data before embarking on a health research prioritisation exercise. Estimates of the DALY have served to pinpoint where there are inadequacies in the health data, to consolidate and interpret what data are available and often has served as the catalyst for developing innovative ways of collecting necessary information. Furthermore, when compared to other similar measures, it has been considered to be the best option as a measure of health outcome for research prioritisation. In addition, the DALY is still in the process of being developed and global burden of disease measures are being updated as better country-specific data become available. The originators of the DALY have also readily responded to specific criticisms. The WHO Ad Hoc Committee on Health research has used the DALY to estimate future health burden and identify health research priorities on a global scale. Above all, there is the argument by Black and McLarty (1996) which is fully supported in this study, that the DALY should only serve to inform the decision-making process and not replace it. The DALY should be viewed only as a part of the entire process of setting health research priorities.

The main recommendation for prioritising health research is that the systematic, step-wise approach laid out in Table 7 be applied to identify and prioritise specific health research. Both a health problem approach and a systems approach need to be adopted to meet the challenges identified. In addition a detailed audit of health research expenditure is needed. Two additional recommendations are that 1) ENHR be fully implemented and 2) a complete national burden of disease study using DALYs, be undertaken. It is envisaged these recommendations will be utilised to develop an explicit, indigenous process of setting health research priorities in South Africa.

A pilot study currently underway is reported in the second annual report of the Global Forum for Health Research (The 10/90 Report on Health Research 2000). This study incorporates the criteria and principles for the main priority-setting approaches. The Combined Approach proposed by the Global Forum for Health includes the ENHR approach, the Five Step Process of the AD Hoc Committee on Health Research and the Visual Health Information Profile proposed by the Advisory Committee on Health Research. These are then linked

with the actors and factors at various levels that determine the health status of a population. This is in the format of an information matrix for setting priorities in health research. (See Appendix 3)

The first part is a situational analysis based on step I of the Ad Hoc Committee and a Visual Health Information Profile. The next part comprises all available information for steps II to IV of the five-step process. It is envisaged that one such matrix table be filled in for each major disease. The global or national priority research agenda can be defined on the basis of priorities for each disease and across diseases. This tool will highlight important gaps in the information needed to make evidence-based decisions on priorities and allow some decisions to be made despite limited information. (The 10/90 Report on Health Research 2000).

This pilot study aids the synthesis of the chapters by illustrating how the various aspects of priority setting can be combined. It should be closely examined as it may be helpful in providing practical guidelines for South Africa to utilise for health research priority setting. Overall it contributes to the on-going development of the process of setting priorities for health research.

6.3 GENERAL RECOMMENDATIONS

6.3.1 POLICY ANALYSIS

Health policy analysis is referred to throughout this study. However, only health research priority setting has been examined in terms of the *context*: South Africa, a developing country; *process*: how priorities are set?; *content*: what information is used, or what measurement results in what priorities?; and the *actors*: who?

Ideally, what is required, is a thorough policy analysis of the entire South African health system using Walt's (1996) terms of context, content and process including the actors involved. It should be noted that it is not the money spent, but the policy, that is paramount for national health research priority setting.

6.3.2 HEALTH INFORMATION

Good health information is a prerequisite for setting both health research priorities and a successful ENHR programme. Prioritisation is an information driven and iterative process. The setting of priorities is not a one-off exercise. Health status changes and as a result it is necessary to re-evaluate priorities on an ongoing basis (see Figure 6, Chapter 2). In terms of information, various initiatives “place South Africa in a position to make meaningful estimates of the national burden of disease with DALYs” (Bradshaw 1996). A South African National Health Information System (NHIS/SA) is evolving that will provide vital health status information on which judgements for health research priorities are based. The interim results of the first national Demographic and Health Survey (1999) has recently been published, providing useful data for priority setting. The National Audit and Foresight exercises set up by the Department of Arts, Culture, Science and Technology in order to establish what research capacity is available and what research should be prioritised will also contribute to this process (The National Research and Technology Foresight Project 1999).

6.3.3 CAPACITY DEVELOPMENT

In the long term, countries must increase the internal capacity to analyse their health problems and needs, set priorities, design, implement and evaluate health research.

The priority setting process will be aided by both building on existing capacity and using mechanisms already in place. Existing mechanisms should be used and include those that assist in gauging progress towards equity in health in South Africa. Needs have been identified such as additional capacity for conducting cost-effectiveness analyses for various health research options. Many more health economists need to be trained for large scale economic analyses for priority setting.

The results of the Foresight exercise are to be used in formulating research capacity-building programmes for the higher education sector. Another area pinpointed for capacity development that aids health research prioritisation, is information and communication technologies (ICT).

Health research priority setting is essentially a future-oriented exercise. The focus of Research and Development initiatives should be the development of ways for predicting future health scenarios in South Africa, as well as the solutions to these future problems.

In addition innovative mechanisms must be developed for incorporating equity into health research priority setting.

6.3.4 FUNDING/EXPENDITURE

The National Technical Committee emphasised the role of funding and argues that funding must follow priority setting (Essential National Health Research 1995). In addition, they suggested that there must be a bidding process to ensure an equitable spread of projects across research entities. There is a need for greater clarity on current health research spending in South Africa, in order to implement and evaluate an ENHR strategy (Harrison and Yach 1995). It is important to evaluate not only lump sums of money spent on health research by the science councils, universities and technikons, the government and NGOs, but to answer questions such as whether the trend of under-funding public health research remains. In particular, the ENHR Congress of 1996 ranked the health problems in South Africa and it is important to assess whether funds have been allocated to these problems. It is also necessary to assess whether funding to Historically Black Universities (HBUs) has increased as well as the nature of research funded. The public sector needs better budgeting and expenditure reporting procedures that reflect the areas of research and specific research types. Funding allocated to and within research organisations must be disaggregated according to the priority problems. There is a need for more detail on both expenditure and the nature of research in the private sector which includes national and international pharmaceutical companies. This funding information needs to be utilised by the ENHR partners to redirect the funding to appropriate health research.

The National Research and Technology Foresight Project (1999) recommends that the funding of health research in South Africa should occur within the ENHR framework. Furthermore, research funding should be coordinated by the Department of Health (DoH) with DACST and the Department of Education (DoE).

“Since democratisation the South Africa government has attempted to re-prioritise expenditure. There is a need to focus on the impact of this expenditure on poor individuals and households. While public expenditure reviews are a useful tool for such analysis, they are usually a major exercise requiring highly detailed information. South Africa must develop capacity to undertake more comprehensive expenditure reviews as part of the monitoring and evaluation of policy implementation” (Poverty and Inequality in South Africa 1998 P 8).

6.3.5 EQUITY

Both a health systems and a health-problem perspective has been used in the priority setting exercise in South Africa. It is necessary to look at the relative balance of these two orientations. We believe that the health-problem approach has predominated in South Africa as well as in the Ad Hoc report, largely as a result of the capacity to quantify it more readily. While a health-problem approach yields a combination of biomedical, clinical and health systems research, we contend that it will be slanted towards a biomedical/health service model as the categories being ranked are diseases, risk factors, technologies or health interventions. Broad developmental aspects of health or cross-cutting system issues will not be prioritised through such an analysis. Special attention needs to be given to inequalities in health as part of the process to redress social injustice. Gwatkin and Heuveline (1997) have shown that the burden of disease approach in analysing health-care needs has limitations when considering the needs of the poor.

The “ENHR mechanism will need to monitor both movement towards equity in health (gauged by both health outcomes and health service outputs/processes/inputs) and equitable use of resources available for health research” (How to Boost the Impact of Country Mechanisms to Support ENHR 1999 P 4). This monitoring process will be aided by, for instance, the South African Health Systems Trust which publishes an annual review focusing on progress toward equity.

6.3.6 COMMUNITY PARTICIPATION IN PRIORITY SETTING

An integral part of ENHR is community involvement. How this will be applied to setting priorities in health research remains a challenge in South Africa. So far there has been little community involvement in the health research priority setting exercise. The National

Technical Committee stated it will be necessary to develop priorities at different levels and ensure that linkages occur between the various levels of decision making (Essential National Health Research 1995). For example, community input into health research prioritisation should feed into the system at the district /local level. The sound foundation of a partnership between health service providers and the community would facilitate this.

The National Research and Technology Foresight Project (1999) recommends a national health research priority setting process that with the participation of civil society focuses on co-ordinating multi-disciplinary, district and provincial priority setting processes at various levels.

6.3.7 THE GLOBAL RESEARCH AGENDA

Medical research has the potential to benefit all of mankind. Although the focus is the establishment of national health research priorities, it is also important to engage at the global level of health research prioritisation.

Following the work of the Ad Hoc Committee the Global Forum for Health Research was established to continue the efforts to focus research on the needs of the poor. South African research priorities have a large overlap with the international research agenda. It is therefore important for South Africans to participate actively in this Forum.

Developing countries need to improve data bases for health measures as well as develop health research prioritisation processes. "The analysis at the global level could then be continually enhanced by the data-based contributions from specific countries" (Essential National Health Research and Priority Setting 1997, P 59). The goal is one of true partnership, a collaborative relationship not a new dependency. South Africa must be in a position, i.e. have sufficient capacity to contribute to the global health research prioritisation process.

In support of the renewed Health-for-All programme of the WHO, the Advisory Committee for Health Research has embarked on PLANET HERES" (Essential National Health Research and Priority Setting 1997). "Planet HERES" stands for Planning Network for

Health Research. “PLANET HERES will promote ongoing operational health research planning and networking, capable of generating a global consensus among participating scientists in defining health-related research priorities for WHO” (WHO 1997 P 38). “This is an integrated tool that makes use of computational logic and visualisation techniques among others, to inform research priority setting and resource allocation” (Essential National Health Research and Priority Setting 1997 P 2). In addition, it is proposed to develop worldwide intelligent research networks. Both planet HERES and the global intelligence networks will make use of evolving ICTs. This computer-supported work will be based on multi-disciplinary data and transnational scientific and technical cooperation (WHO 1997). In the new information age South Africa cannot afford to be excluded from these sophisticated and technologically-advanced global research prioritisation initiatives. To participate and obtain optimal benefits, there is a need to keep abreast of new developments in the field.

6.4 RESEARCH TO IMPROVE HEALTH RESEARCH PRIORITISATION IN SOUTH AFRICA

Future research should include monitoring the health research prioritisation process in South Africa. An important issue for all future health research concerns the quality of health research, i.e. the issue of research excellence for priority research. The Bangkok Declaration from the International Conference on Health Research for Development in 2000, states that use be made of high quality research. In addition, there should be a strong ethical basis governing the design, conduct and use of research. The Declaration states that there should be a commitment that knowledge derived from public finds should be available and accessible to all.

The collection of health information falls into the ambit of health research. The Departments of Home Affairs and Health should improve the quality of birth and death registration as the basis of health status data for the National Health Information System. There should be a focus on collecting data on morbidity and disability.

For a situational analysis at the start of a priority setting exercise, there is a need for an audit of expenditure as well as the type of research currently underway in South Africa. In addition, comparative studies on health research priority setting in developed countries as

well as developing countries especially those using an ENHR approach, will benefit the process in South Africa.

The inclusion of the community in research prioritisation is a vital component of the process. The various means of including people at grassroots level in the exercise of setting health research priorities needs to be explored.

There has been no overall, systematic health policy analysis applied in this study. A policy analysis of the entire health system in South Africa will greatly assist the implementation of priority health research programmes once these are established. This includes analysis on how health research prioritisation fits into the health reform process in South Africa.

The discussion of the South African ENHR Prioritisation Congress included details of what priorities emerged through this particular process in South Africa. Future research should include a more detailed analysis the health research priorities established at the first ENHR priority setting congress.

In terms of the application of international experience being used in South Africa, developing countries such as Mexico, Mozambique, Thailand and the Philippines which have adopted an ENHR strategy can serve as case studies to ascertain how health research priorities are determined within the ENHR program in different countries.

APPENDICES

Appendix 1: The DALY formula

Appendix 2: The HeaLY formula

Appendix 3: The Combined Approach: a practical framework for setting priorities in health research

APPENDIX 1

The DALY formula

The duration of time lost due to premature mortality is calculated using standard expected years of life lost, where model life-table West with an expectation of life at birth of 82.5 for females and 80 for males has been used. Time lived at different ages has been valued using an exponential function of the form $Cxe^{\beta x}$. Streams of time have been discounted at 3%. A continuous discounting function of the form $e^{-r(x-a)}$ has been used where r is the discount rate and a is the age of onset.^h Disability is divided into six classes, with each class having a severity weight between 0 and 1. Time lived in each class is multiplied by the disability weight to make it comparable with the years lost due to premature mortality.

A general formula for the number of DALYs lost by one individual can be developed:

$$\int_{x=a}^{x=a+L} DCxe^{-\beta x} e^{-r(x-a)} dx$$

The solution of the definite integral from the age of onset a to $a+L$ is the duration of disability or time lost due to premature mortality provides the DALY formula for an individual:

$$- \left[\frac{DCe^{-\beta a}}{(\beta + r)^2} \left[e^{-(\beta+r)(L)} (1 + (\beta + r)(L + a)) - (1 + (\beta + r)a) \right] \right]$$

where D is disability weight (or 1 for premature mortality), r is the discount rate, C is the age-weighting correcting constant, β is the parameter from the age-weighting function, a is the age of onset, and L is the duration of disability or time lost due to premature mortality. This formula can be conveniently written in a spreadsheet cell to facilitate calculation of DALYs. In the specific formula used for calculating DALYs, r equals 0.03, β equals 0.04 and C equals 0.16243.

Source: Murray (1994)

APPENDIX 2

Variables for Healthy Life-Years (HeaLY) Estimation

| Sign | Explanation | Expression |
|-------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------|
| I | Incidence rate per 1000 population per year | Per 1000 per year |
| Ao | Average age at onset | Years |
| Af | Average age at death | Years |
| E(Ao) | Expectation of life at age of onset | Years |
| A(Af) | Expectation of life at age of death | Years |
| CFR | Case fatality ratio: proportion of those developing the disease who die from the disease | 0.00 - 1.00 |
| CDR | Case disability ratio: proportion of those developing the disease who have disability from the disease | 0.00 - 1.00 |
| De | Extent of disability (from none to complete disability equivalent to death) | 0.00 - 1.00 |
| Dt | Average duration of disability for those disabled by the disease; a composite of temporary and permanent disability based on the proportion of cases in each category | Years |
| HeaLY | Healthy life years lost per 1000 population per year: $I \times \{ [CFR \times \{E(Ao) - [Af - Ao]\}] + [CDR \times De \times Dt] \}$ | HeaLYs per 1000 per year |

Source: Hyder et al. (1998)

| | | Actors/factors determining the health status of a population (intervention levels) | | | |
|------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Five Steps in Priority Setting | | Level of the individual, family and community | Level of the health ministry, health research institutions, and health systems and services | Level of sectors other than health | Level of central government and macroeconomic policies |
| I. What is the burden of the disease/risk factor? | Data and Analytic Requirements Health status Assessment of the burden of disease (DALYs, QUALYs, etc) | | | | Tool of analysis: Visual Health Information Profile (VHIP) proposed by the Advisory Committee on Health Research |
| II. Why does the burden of disease (BoD) persist? What are the determinants? | Acquisition of knowledge about disease determinants | Analysis of: • Individual determinants • Family determinants • Community determinants influencing the BoD | Analysis of: • Biomedical knowledge • Health policies • Health systems • Health services influencing the BoD | Analysis of sectoral policies having an impact on the BoD, for example: • Education • Environment • Working conditions • Security policies | Analysis of macroeconomic policies having an impact on the BoD, for example: • Budget policies, structural adjustment programmes • Research policies • Good governance |
| III. What is the present level of knowledge? | What is known today about existing interventions? How cost-effective are they? | Knowledge about factors influencing the C/E* of interventions at: • Individual level • Family level • Community level | Knowledge about factors influencing the C/E of interventions in: • Biomedical research • Health policies • Health systems • Health services | Knowledge about factors influencing the C/E of interventions in sectors outside health for example: • School training in hygiene • Nutrition campaign • Pollution control | Knowledge about factors influencing the C/E of changes in macroeconomic policies, for example: • Structural adjustment programmes and health • Research policies • Good governance |
| IV. How cost-effective could future interventions be? | Is research likely to produce more cost-effective interventions than the present ones? | Estimated C/E of potential interventions at: • Individual level • Family level • Community level | Estimated C/E of potential interventions in: • Biomedical research • Health policies • Health systems • Health services | Estimated C/E of potential interventions in various sectors outside health: • School training in hygiene • Nutrition campaign • Pollution control | Estimated C/E of potential changes in macroeconomic policies, for example: • Structural adjustment programmes and health • Research policies • Good governance |
| V. What are the resource flows for that disease/risk factor? | Assessment of the public and private resource flows. | | | | |

Source: The 10/90 Report on Health Research 2000

*C/E: cost-effectiveness

REFERENCES

A National Health Plan for South Africa. (1994). Prepared by the ANC Health Department with technical support of World Health Organisation and UNICEF. ANC Health Department. January 1994. Johannesburg. (second draft).

A Research Policy Agenda for Science and Technology - to support global health development: A synopsis. (1997) The Advisory Committee on Health Research. World Health Organization, Geneva.

Advisory Committee On Health Research (1995). DALY Review Group. 17-20. World Health Organization. Geneva. (draft)

Advisory Committee On Health Research (1996). ACHR News. *Bulletin of the World Health Organization*; **74**(3): 333-335.

AIDS Bulletin, **8**(4): December 1999. Tygerberg. South Africa. ISSN 1019-8334.

AIDS epidemic update: December 1999. UNAIDS Joint United Nations Programme on HIV/AIDS. World Health Organisation (UNAIDS 20 Avenue Appia 1211 Geneva 27 Switzerland).

Alma Ata 1978: *Primary Health Care.* (1978). WHO. Geneva.

Anand S and Hanson K. (1996). *Disability-Adjusted Life Years: A Critical Review.* Center for Population and Development Studies. Harvard University. Cambridge. (draft)

Anand S and Hanson K. (1997). Disability-adjusted life years: a critical review. *Journal of Health Economics*, **16**: 658-702.

Barendregt L, Bonneux L. and Van der Maas P J. (1996). DALYs: the age-weights on balance *Bulletin of the World Health Organization*; **74**(4): 439-443.

Barker C and Green A. (1996). Opening the debate on DALYs. *Health Policy and Planning*; **11**(2): 179-183.

Barron P, Edwards J, Makhanya N, Palmer N, Bradshaw D, Zwarenstein M. and Makubalo L. (1997). Health Systems Trust, Health Systems Research in South Africa. *S Afr Med J* (Public Health Issue); **87**: 236-237.

Barker C (1996). *The Health Care Policy Process.* Sage Publications Ltd. London.

Berman P and Ormond B A. (1988). Changes in health care demand and supply accompanying economic development. *Research in Human Capital Development*; **5**: 147-172.

Black J, McLarty D. (1996) The DALY boon or burden. (For Debate) *S Afr Med J* (Public Health); **86**(11): 1479-1481.

Blecher M S and McIntyre D. (1995). Expenditure on health research in South Africa, National Research and Technology Audit 1991/1992. *S Afr Med J* ; **85**: 365-370.

Bobadilla J L and Costello C. (1996) *Mortality profiles and adult health interventions in the Newly Independent States. Overview*. In: Bobadilla, J. L and Costello, C. *Mortality profiles and adult health interventions in the Newly Independent States*. National Academy Press. Washington D.C. (forthcoming)

Bobadilla J L. (1996). *Priority Setting and Cost Effectiveness*. In: Janovsky, K. ed. *Health policy and systems development. An agenda for research*. World Health Organization; 43-60. Geneva.

Bowie C, Beck S, Bevan G, Raftery J, Silverton F and Stevens A. (1997). Estimating the burden of disease in an English region. *Journal of Public Health Medicine*; **19**(1): 87- 92.

Bradshaw D. (1996). Is the DALY measurable in South Africa. *S Afr Med J*; **86**(11): 1483.

Bradshaw D, Bourne D E, Schneider M and Sayed R. (1995). *Mortality patterns of chronic lifestyle in South Africa* In: Fourie J and Steyn K. ed. *Chronic Diseases of Lifestyle in South Africa. Review of research and identification of essential health research priorities*. MRC Technical Report; 5-35. Tygerberg. South Africa. ISBN 1-874826-47-1.

Bradshaw D, Botha J L, Joubert G, Pretorius J P G, Van Wyk R, Yach D. (1987). *Review of South African Mortality (1984)*. MRC Tech Rep 1. May 1987. Tygerberg. South Africa.

Bronzino D B, Smith V H and Wade M. (1990). *Medical Technology and Society. An Interdisciplinary Approach*. The MIT Press, Cambridge Massachusetts.

Bryant J H, Kahn K S and Hyder A A. (1997). Ethics, equity and renewal of World Health Organisation's health-for-all strategy. Round Table. *World Health Forum*; **18**: 107-115.

Brundtland (1998) G H. Director-General. World Health Organisation. 15 December 1998. Speech on burden of disease concept.

Bunker J P, Frazier H S and Mostelle F. (1994). Improving health: measuring effects of medical care. *Millbank Quarterly*; **72**(2): 225 - 258.

Caldwell J C. (1993). Health Transition, The Cultural, Social and Behavioral Determinants of Health in the Third World. *Soc Sci Med* 1993; **36**(2): 125-135.

Cape Times, Thursday August 10, 2000. *Women 'poorest of poor'*. Monare M. P5.

Cooper R S, Osotimehin B, Kaufman J S and Forrester T. (1998). Disease burden in Sun-Saharan Africa what should we conclude in the absence of data? *Lancet*; **351**: 208-210.

Cooper O, Weil D E, Alicbusan A P, Wilson J F, Reich M R and Bradley D J. (1990) *The impact of development policies on health A review of the literature*. World Health Organization, Geneva.

DALYs and Reproductive Health - some preliminary concerns. (1998[a]) Division of Reproductive Health, (Technical Support). World Health Organization. Geneva. (draft)

DALYs (Disability Adjusted Life Years) and Reproductive Health: A critical analysis. (1998[b]). (AbouZahr, C.) Reproductive Health. World Health Organization. Geneva. (draft)

DALYs (Disability Adjusted Life Years and Reproductive Health). (1998[c]). Conference Reports. World Health Organization. 27-28 April 1998 Geneva. (draft)

DALYs and Reproductive Health: Report of an informal consultation 27-28 April 1998. (1999). Division of Reproductive Health. (Technical Support). World Health Organization. Geneva.

Dempsey M. (1947) Decline in tuberculosis. The death rate fails to tell the entire story. *American review of tuberculosis*. **56**: 157-164.

Designing and Implementing a National Burden of Disease Study Handbook. 12-21 November 1996. Stowe, Vermont, USA. Burden of Disease Unit. Harvard Center for Population and Development Studies.

DISMOD (1996) <http://www.hsph.harvard.edu/organizations/bdu>.

Dorrington R. (1999). *AIDS, Then Now Tomorrow*. Third African Population Conference. The African Population in the 21st Century. 6-10 December 1999, Durban, South Africa.

Drummond M F, Stoddart G I and Torrance G W. (1987) *Methods for the economic evaluation of health care programmes*. Oxford University Press, Oxford.

Essential National Health Research (1991[a]). In: *Changing Health In South Africa: Towards New Perspectives in Research*. The Henry J Kaiser Family Foundation, 55-80. California.

Essential National Health Research. A Strategy for Action in Health and Human Development. (1991[b]). Task Force on Health Research for Development. Geneva. Switzerland.

Essential National Health Research. Report of the National Technical Committee. (1995) - as appointed by the Minister of Health Dr N. C. Dlamini Zuma. November 1995. Chairperson, Professor K C Househam. Bloemfontein.

Essential National Health Research and Priority Setting: Lessons Learned. (1997). Council on Health Research and Development (COHRED) document 97.3: June 1997. Geneva.

EuroQol Group. (1990). "EuroQol - a new facility for the measurement of health-related quality of life." *Health Policy*; **16**: 199-208.

Feachem R G, Graham, W J and Timaeus I M. (1989). Identifying health problems and research priorities in developing countries. *J Trop Med and Hyg*; **92**: 33-191.

Foege W. (1994). Preventative Medicine and Public Health. *JAMA*; **271**(21): 1704-1705.

Foltz A. (1996). *The Policy Process*. In: Janovsky K, ed. *Health policy and systems development. An agenda for research*. 207-223. World Health Organization. Geneva.

Frenk J. (1993). The New Public Health. *Annu. Rev. Publ. Health* **14**: 469-90.

Frenk J. *The Health-Care Transition: Concepts And Policies on the Dynamics of Health Systems*. Prepared for the seminar series on the Health Transition, Harvard Center for Population and Development Studies. (draft, circa 1995)

Frenk J. (1995). Comprehensive policy analysis for health system reform. *Health Policy*; **32**: 257-277.

Frenk J, Bobadilla J L, Sepúlveda J and Cervantes L M. (1989). Health transition in middle-income countries: new challenges for health care. *Health Policy and Planning*; **4**(1): 29-39.

Ghana Health Assessment Project Team. (1981). A quantitative method of assessing the health impact of different disease in less developed countries. *International Journal of Epidemiology*; **10**: 73-80.

Gilson I, Mills A and Berman P A. (1995). *Health Sector Reforms in sub-Saharan Africa: Lessons of the Last 10 Years*. In: Berman, P. A. ed. *Health sector reform: Making health development sustainable*. 278-307. Harvard University Press. Boston, Massachusetts.

Goerdt, A. Koplan, J P Robine, J M Thuriaux, M C and van Ginneken, J K. (1996). *Non-fatal Health Outcomes: Concepts, Instruments and Indicators*. In: Murray, C. J. L. and Lopez, A. D. eds. (1996[a]) *Global Burden Of Disease And Injury Series. The Global Burden Of Disease*. World Health Organization. Geneva.

Gray A. (1993). *World patterns of mortality*. (1993). In: Gray A. ed. *World Health and Disease*. Chapter 2, 6-20. Open University Press. London. Philadelphia.

Green A. (1992). *An Introduction To Health Planning In Developing Countries*. Oxford: Oxford University Press; **13**: 185.

Groenewald P. (1996). *Summary of the Findings. Investing in health research and development. Report of the Ad Hoc Committee on health research relating to future intervention options*. CERSA, Medical Research Council. Cape Town. South Africa.

Gross C P, Anderson G F, Powe N R. (1999) The relation between funding by the National Institutes of Health and the Burden of Disease. (Special article) *New Eng J Med*; **340**(24): 1881-1887.

Growth, Employment and Redistribution, (GEAR), (1996) A Macroeconomic Strategy
<http://www.polity.org.za/govdocs/policy/growth.html#ch1>

Gwatkin D R and Heuveline P. (1997). *The Cause And Age Structure Of Death Among The Global Poor. An Initial Assessment of the Global Burden of Disease from a Poverty and Equity Perspective*. Prepared for the Global Forum for Health Research, with support from The World Bank and the Government of Norway. The World Bank. Washington D.C. (draft)

Gwatkin D, Guillot M. (1998). *The Burden of Disease among the Global Poor: Current Situation, Trends and Implications for Research and Policy*. Prepared for the Global Forum for Health Research. The World Bank. Washington D.C.

Ham C. (1995[a]). Priority setting in the NHS. *Br J Health Care Management*; **1**: 27-29.

Ham C. (1995[b]). *Priority Setting For Health*. In: Janovsky, K. ed. *Health policy and systems development. An agenda for research*; World Health Organization, Geneva: 25-42.

Harrison D and Yach D. (1995). *Research and Development*. In: *South African Health Review*. 13-138. Health Systems Trust and Henry J Kaiser Family Foundation. Durban. South Africa.

Harrison D. *Does ENHR Tilt at Windmills?* (1999). Research into Action. The Newsletter of the Council on Health Research for Development. (COHRED). Issue 16, January-March 1999.

Health Systems Trust. Research Programme: A framework for Health Systems Research 1999 - 2001. (1999) 1-11. HST. Durban. South Africa. (draft)

Health Research: Essential Link To Equity In Development. (1990). Commission on Health Research for Development. Oxford: Oxford University Press.

HealthLink Bulletin. 25 February 2000. HST. Durban. South Africa.
hinfo-1@healthlink.org.za.

How to Boost the Impact of Country Mechanisms to Support ENHR: A peek into the melting pot of country experiences. (1999). COHRED Working Group on Promotion, Advocacy and the ENHR Mechanism. February 1999. Press Gang. Durban. (COHRED c/o UNDP, Palais des Nations CH-1211 Geneva 10 Switzerland) COHRED.
<http://www.cohred.ch>

Hyder A A, Rottland G and Morrow R H. (1998). Measuring the burden of disease: healthy life-years. *Am J Public Health*; **88**: 196-202.

International classification of impairments, disabilities, and handicaps: a manual of classification relating to the consequences of disease. (1980). WHO. Geneva.

Investing in Health Research and Development. Report of the Ad Hoc Committee on Health Research Relating to Future Intervention Options. (1996). World Health Organization. Geneva.

Jamison D T, Sexenian H, Bergevin Y. (1995). Investing in Health Wisely - The Role of Needs-based Technology Assessment. *Int J Tech Assesm Health Care* **11**(4); 673-684.

Janovsky K and Cassels A. (1996). *Health policy and systems research: Issues, Methods, Priorities.* In: Janovsky K, ed. *Health policy and systems development. An agenda for research.* 11-23. World Health Organization. Geneva.

Kaplan G A, Haan N H, Syme L S, Minkler M and Winkleby M. (1987). *Socioeconomic Status and Health.* In: Amler RW, Dull HB, eds. *Closing the Gap. The Burden of Unnecessary Illness.* Oxford University Press, New York, Oxford.

Katzenellenbogen J. (1991). *Disability Studies.* In: Katzenellenbogen J, Joubert J, Yach D, eds. *Introductory manual for Epidemiology in Southern Africa.* Medical Research Council. Tygerberg. South Africa. ISBN 1-874826-05-6

Laloo R. (1995). Equity in health - revisited. *CHASA Journal of Comprehensive Health;* **6**(4): 199-201.

Legge D. (1993). *Investing In The Shaping Of World Health Policy.* Prepared for presentation at the AIDAB, NCEPH and PHA workshop to discuss the World Bank's 16th World Development Report, Investing in Health. Canberra.

Lerer L B. (1997) *The Application of Strategic Management Theory in Global Public Health - Towards a Model of Health Determinants, Health Status and Interventions.* Research Report. Graduate School of Business. University of Cape Town.

Lerer L B, Lopez A D, Kjellstrom T, Yach D. (1998). Health for all: analyzing health status and determinants. *Wld hlth quart.*, **5**: 7-20.

Lowenson R, Sanders D and Davies R. (1991). Challenges to equity in health and health care: A Zimbabwean case study. *Soc Sci Med;* **32**: 1079 -1088.

Macro-economic policy and its impact on health development, employment, redistribution and crime. National Progressive Primary Health Care Network. Position paper. NPPHCN, August, 1996. Johannesburg. (second draft)

Mathers C, Vos T, Stevenson C. (1999). The burden of disease and injury in Australia. Australian Institute of Health and Welfare, Canberra. ISBN: 1 74024 0197.

MBewu A, Mngomezulu K (1999). In: *South African Health Review 1999.* Chapter 27. HST. Durban. South Africa. <http://hst.org.za/sahr/99/chap27.htm>

MBewu A D. (1996). South African medical research - ugly stepsister or fair godmother? *S Afr Med J*; (editorial) **86**(5): 515-516.

McKeown T. (1976[a]). *The Modern Rise of Population*. Edward Arnold. London. England.

McKeown T. (1976[b]). *The role of medicine: dream, mirage, or nemesis*. The Nuffield Provincial Hospitals Trust. London. England.

McKeown T, Record R G and Turner R D. (1975). An interpretation of the decline in mortality in England and Wales during the twentieth century. *Population studies*; **29**: 391-422.

Melse J M, Essink-Bot M L, Kramers P G N and Hoeymans N. (2000). A National Burden of Disease Calculation: Dutch Disability-Adjusted Life-Years. *Am J of Publ Health*; **90**(8): 1241-1247.

Mooney G H and Drummond M F. (1982). Essentials of Health Economics. Part IV (continued) - Organizing health care services. *Br Med J*; **2585**: 1485-1486.

Mooney G, Irwig L and Leeder S. (1997). Priority setting in health care: unburdening from the burden of disease. *Aust N Z J Public Health*; **21**: 680-681.

Morrow R H and Bryant J H. (1995). Health Policy Approaches to Measuring and Valuing Human Life: Conceptual and Ethical Issues. *American Journal of Public Health*, 1995; **85**(10): 1356-1360.

Mosley WH and Chen LC. (1984). An analytical framework for the study of child survival in developing countries 25-45. *Population and development review*, **10** (suppl.): 25-45.

Mosley W H, Bobadilla J L and Jamison D T. (1993). The Health Transition: Implications for Health Policy. In: Jamison, D T. Mosley, W H., Measham, A R., Bobadilla, J L. ed. *Disease Control Priorities in Developing Countries*. 673-702. Oxford University Press. New York:

MRC Annual Report 1999-2000. Tygerberg. South Africa. ISBN 1-874826-73-0.

MRC News. **30**(3), Sept. 1999. Tygerberg. South Africa. ISSN 1017-611X. <http://www.mrc.ac.za>.

MRC Update '98. (1998) Tygerberg. South Africa. ISBN 1-874826-80-3

Murray C J L. (1990). Rational approaches to priority setting in international health. *J Trop Med and Hyg*; **93**: 303-311.

Murray C J L. (1994). Quantifying the burden of disease: the technical basis for disability-adjusted life years. *Bulletin of the World Health Organisation*; **72**(3): 429-445.

Murray C J L. (1996). *Rethinking DALYs*. In: Murray C J L and Lopez A D. (1996[a]). ed. *The Global Burden of Disease. A comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020*. Harvard School of Public Health; 1-98. Harvard University Press. Cambridge.

Murray C J L and Acharya A K. (1997). Understanding DALYs. *Journal of Health Economics*; **16**: 703-730.

Murray C J L and Chen L C. (1993). In search of a contemporary theory for understanding mortality change. *Soc Sci Med*; **36**(2): 143-155.

Murray C J L and Lopez A D. (1994). *Global Comparative Assessments in the Health Sector. Disease Burden, Expenditures and Intervention Packages*. World Health Organization, Geneva.

Murray C J L and Lopez A D. (1996[b]). The incremental effect of age-weighting on YLLs, YLDs, and DALYs: a response *Bulletin of the World Health Organization*; **74** (4): 445- 446.

Murray C J L and Lopez D. (1996[c]). Evidence-Based Health Policy - Lessons from the Global Burden Of Disease Study. *Science* 1996; **274**: 740-743.

Murray C J L and Lopez A D. (1997[a]). The utility of DALYs for public health policy and research: a reply. *Bulletin of the World Health Organization*; **75**(4): 377-381.

Murray C J L and Lopez A D. (1997[b]). Regional patterns of disability-free life expectancy and disability-adjusted life expectancy: Global Burden of Disease Study. *The Lancet*; **349**: 1347-1352.

Musgrove P. (2000) A critical review of 'A critical review': the methodology of the 1993 World Development Report, 'Investing in Health.' *Health Policy and Planning*; **15**(1):110-115. National Department of Health, Directorate: Health Systems Research, Research Co-ordination & Epidemiology, April 2000. Pretoria. South Africa.

National Research and Technology Foresight Project. Health Foresight (1999). The Department of Arts, Culture, Science and Technology. Pretoria. South Africa. ISBN 0-7970-3797-7.

Neufeld V. (1996). *South Africa ENHR Site Visit - Summary Report*. Department of National Health. Pretoria.

Omran A. (1971). The Epidemiologic Transition A Theory of the Epidemiology of Population Change. *Millbank Memorial Fund Quarterly*; **49**: 509-538.

Paalman M, Bekedam H, Hawken L and Nyheim D. (1998). A critical review of priority setting in the health sector: the methodology of the 1993 World Development Report. *Health Policy and Planning*; **13**(1): 13-31.

Parry C D H, Yach D and Tollman S M. (1992). The setting of health research priorities in a new South Africa. *S Afr Med J*; **82**: 306-308.

Patrick D L and Erickson P. (1993). *Health Status and Health Policy. Allocating Resources to Health Care*, Oxford University Press.

Poverty and Inequality in South Africa. Report prepared for the Office of the Executive Deputy President and the Inter-Ministerial Committee for Poverty and Inequality. Summary Report. 13 May 1998.

<http://www.polity.org.za/govdocs/report/poverty.html>

Price M. (1988). The consequences of health service privatization for equality and equity in health care in South Africa. *Soc Sci Med*; **27**: 703-716.

Proceedings of the First Essential National Health Research Congress on Priority Setting. November 14-15, 1996. Directorate Research Coordination and Management. Department of National Health. Pretoria. South Africa.

Public Health Status and Forecasts. The health status of the Dutch population over the period 1950-2010. (1994). Ruwaard D, Kramers P G N, Van den Berg Jeths A, Achterberg P W, eds. Sdu Uitgeverij Plantijnstraat, The Hague. Netherlands.

Research into Action. (1997). COHRED. Issue 8 January - March 1997. C/O UNDP, Palais des Nations, CH-1211 Geneva 10, Switzerland.

Robine JM. (1998). Measuring the burden of disease. *The Lancet*; **352**: 757-758.

Ronayne J. (1984). *Science in government*. Edward Arnold. London.

Sayers B, McA. and Fliedner, T M. (1997). The critique of DALYs: a counter-reply. *Bulletin of the World Health Organization*; **75** (4): 383-384.

Schneider M, Bradshaw D. Setting health research priorities: Lessons from South Africa. (draft, December 2000).

South Africa Demographic and Health Survey 1998, Preliminary Report. (1999). Department of Health, Medical Research Council and Macro International Inc. Pretoria. South Africa.

Stevens M. (1997). *Health* In: Budlender, D. ed. *The Second Women's Budget*. Idasa; 286-313. Creda Press. Cape Town.

Sullivan D F. (1971). A single index of mortality and morbidity. *HSMHA Health reports*, **86**: 347-354.

Sunday Times, October 24 1999. Richer man, poorer man. Jacobson C: P 19.

Sunday Times, Business Times. July 27 1997. *Sloppy planning cripples good intentions*. Strachan B; P 28.

Susser M. (1993). Public Health Then and Now. Health as a Human Right: An Epidemiologist's Perspective on the Public Health. *American Journal of Public Health*, **83** (3): 418-426.

Synthesis Report Of The National Research And Technology Audit. Prepared by the Foundation for Research Development for the Department of Arts, Culture, Science and Technology. 1998: Chapter 3. Pretoria. South Africa.
<http://www.dacst.gov.za/syntrep.htm>

Szreter S. (1988). 'The importance of social intervention in Britain's mortality decline. 1850-1914: a re-interpretation of the role of public health', *Social History of Medicine*: 1-37.

Tan Torres T. (1997). *Criteria for Priority Setting*. In: *Essential National Health Research And Priority Setting: Lessons Learned*. Council on Health Research and Development (COHRED) document 97.3: 31- 44.

Taskforce On Health Research For Development, Essential National Health Research. Ramalinga-Swami (chairman) October 1991. Geneva.

The 10/90 Report on Health Research 2000 (2000). Global Forum for Health Research. Switzerland, ISBN 2-940286-01-9.

The World Health Report 2000. (2000). World Health Organization. Geneva, ISBN 92 4 156198 X.

The Reconstruction and Development Program. (1994). African National Congress, (ANC), Johannesburg, South Africa.

The development of the World Health Organization Quality of Life Instrument (WHOQOL). World Health Organization measuring quality of life. (1993). Division Of Mental Health. WHO. Geneva. MNH/PSF/93.1.

The SCF Perspective. Investing In Health - World Development Report 1993. Save the Children's Fund Overseas Department. 1 July 1993. London. (unpublished document)

TIME. August 15, 1994. *Africa's Uphill Battle*. Behrens G: P 64. Netherlands.

Tollman S. (1997). *Information For Setting Priorities*. In: *ENHR: Essential National Health Research And Priority Setting: Lessons Learned*. Council on Health Research and Development (COHRED) document 97.3; 7-19. Geneva.

Torrance GW. (1986). Measurement of Health Status Utilities for Economic Appraisal. A Review. *Journal of Health Economics*; **5**: 1-30.

Torrance, G. Thomas, W H. and Sackett, D L. (1972). A utility maximization model for evaluation of health care programmes. *Health services research*. **7**: 118-133.

Van Rensburg D. (1997). Health and Development. In: *South African Health Review*; 17- 27. Health Systems Trust. Durban, South Africa.

Varkevisser C M, Pathmanathab I and Brownlee A. (1991). *Designing and Conducting Health Systems Research Projects. Module 3. Identifying and Prioritising Problems for Research*. Health Systems Research Training Series. 2(1): 34. International Development Research Centre. World Health Organisation. Geneva.

Walt G. (1994). *Health Policy. An Introduction to Process and Power*. Sage Publications Ltd. London.

Walt G. (1996). *Policy Analysis: An Approach*. In: Janovsky, K. ed. *Health policy and systems development. An agenda for research*. 43-60. World Health Organization. Geneva.

Walt G and Gilson L. (1994). Reforming the health sector in developing countries: the central role of policy analysis. *Health Policy and Planning*, 9: 353-370.

White Paper for the Transformation of the Health System in South Africa. (1997) Department of Health. Pretoria. South Africa.

White Paper on Science and Technology. (1996). Department of Arts, Culture, Science and Technology. (DACST) Pretoria. South Africa.

Whitehead H. (1990). *The concepts and principles of equity and health*. World Health Organisation Publication. Regional office for Europe. Copenhagen.

Wilkinson R G. (1996). *Unhealthy Societies The Afflictions of Inequality*. Routledge, London.

World Development Report 1993. Investing in Health. The World Bank, Oxford University Press, Oxford.

World Health Organization. Constitution 7 April 1948. Basic documents. 40th edition. WHO, Geneva.

Zeckhauser, R. Shephard, D. (1976). Where now for saving lives? *Law and contemporary problems*. 40(b): 5-45.

Zwi A B and Mills A. (1995). Health Policy in Less Developed Countries: Past Trends and Future Directions. *Journal of International Development*; 7(3): 299-32.