WHY RESEARCH IN HEALTH AND DISEASE?

C.M. Francis

Research is a systematic process of generating new knowledge. Research in Health and Disease is the generation of new knowledge using scientific methods to improve and maintain the health of the people and to identify the health problems leading to disease and to deal with them effectively and efficiently. Research in Health and Disease is essential to help people to adopt measures conducive to better health and to improve the design of health policy, service delivery and interventions. The focus of the research efforts should be on

- the total health of all the people, and
- annihilating or reducing the burden on the people of diseases. Health Research is a vital investment in the future. The seeds of research sown today will yield a wealth of results effective tomorrow.

Purpose of Research

Health Research is essential in every country to

- determine the country’s particular health problems and set priorities among those problems;
- analyze different measures to deal with those problems;
- help in the choice of appropriate strategies and actions to achieve maximum possible improvement in the health of the people; action without appropriate knowledge can be wasteful;
- develop new tools to attain better health (e.g. improved lifestyles); prevent diseases (e.g. vaccines) and treat diseases (e.g. drugs);
- make interventions cost-effective by proper planning and wise use of scarce resources (e.g., low cost ambulatory treatment of tuberculosis; oral rehydration for diarrhoea);
- evaluate the impact of measures undertaken; and
- advance basic understanding and frontiers of knowledge in health and disease.

Health and Development

There is a strong link between people’s health and the development of the country. Poor health

- reduces healthy life expectancy;
- reduces educational achievement;
- decreases productivity;
- increases poverty and inequity.

Poverty leads to the vicious cycle of malnutrition, low level of education, disease, poor housing and lack of access to health care services

The 10/90 gap

Only about 10% of health research funding is allocated to 90% of the world’s health problems. This serious disparity is caused by the very large disparities in income between the developing countries
and affluent countries. The disease affecting the rich gets the attention of research workers because of market forces. The results of the research done in and for the people of the affluent counties cannot be transferred readily into the low and middle-income countries.

- Communicable diseases represent a large share of the disease burden in the low-and middle-income countries, whereas they have been largely wiped out in the affluent countries.
- Vaccines developed in the affluent countries may not be suitable for developing counties, due to variety of conditions.
- The determinants of health, risk factors, levels of health care systems and services vary.
- The availability, accessibility and utilization of health care facilities vary and especially the factor of affordability.

<table>
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<tr>
<th>Poor Health</th>
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<td>• reduces healthy life expectancy;</td>
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<td>• hinders educational achievements;</td>
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<td>• decreases productivity;</td>
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<td>• increases poverty and inequity.</td>
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### Disease Burden (DALYs per 1,00,000 population), 1998.

<table>
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<tr>
<th>Group of Diseases</th>
<th>Low and middle income counties</th>
<th>High income countries</th>
<th>Ratio</th>
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<tbody>
<tr>
<td>1. Communicable diseases, and nutritional conditions</td>
<td>11,206</td>
<td>863</td>
<td>13</td>
</tr>
<tr>
<td>2. Non-communicable diseases</td>
<td>10,200</td>
<td>9,664</td>
<td>1</td>
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<tr>
<td>3. Injuries</td>
<td>4,198</td>
<td>1,403</td>
<td>3</td>
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### Priority Setting in Health Research

We have to set our priorities correctly, because

- resources (personnel, materials and funds) are limited; and
- there are problems of graded significance with respect to death, disease and disability.

Research priorities should be set, considering also the ethical principles of equity and justice.

We must focus on the determinants of health and on diseases causing the greatest burden of mortality morbidity. We have to consider the determinants of health at the individual, family, community, district, state and national levels.

Who sets priorities? Priorities should be set involving all the people concerned – individuals, families, communities and the governments – local, state and national.

Very often, diseases of significance to the poor are neglected.
### Classification of Diseases

**Commission on Macroeconomics and Health, 2001**

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<tr>
<th>Disease type</th>
<th>Global research effort</th>
<th>Example</th>
<th>Notes</th>
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<tbody>
<tr>
<td>1. Diseases not neglected</td>
<td>High</td>
<td>Cardiovascular diseases, Diabetes</td>
<td>High incentives for R &amp; D</td>
</tr>
<tr>
<td>2. Neglected diseases</td>
<td>Low</td>
<td>Malaria, Tuberculosis</td>
<td>Low accessibility for poor countries</td>
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<tr>
<td>3. Very neglected diseases</td>
<td>Very low</td>
<td>Kala-azar, Lymphatic filariasis</td>
<td>Extremely low R &amp; D funding</td>
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The neglected and very neglected diseases are common in the poor countries. There is very little funding for Research & Development. The very neglected are the ‘orphan’ diseases in which the affluent counties are not interested.

Of the 1233 new drugs that reached the global market between 1975 and 1997, only 13 were for the tropical infectious diseases that affect primarily the poor in low and middle income counties.

### Problems in Research in Health and Disease

Health research is beset by many problems. The more important among them are:

- lack of priority setting;
- insufficient resources (persons, materials, money);
- misallocation of resources;
- ineffective and inefficient use of funds;
- failure to ensure wide dissemination of results;
- failure to ensure that the results of research have an impact on the health of the people.

How to make health research more effective?

- Set the priorities to address the major health problems
- Help correct the 10/90 gap
- Increase the resources for research
- Remove the isolation of research
- Increase the impact of the results on peoples health — improved use of results, better health policy; better services.

Unfortunately, research is often seen as an ‘ivory tower’ by the policy and decision makers and the people themselves. This must change.
Partners in Research

All people and organizations having a stake in health and development should be involved at different stages of research. These include:

- Research oriented institutions
- Universities and teaching institutions
- Government – national, state and local
- Professional organizations
- Civil society
- Health care institutions
- Health workers
- People

Considerable amount of work is being done all over the country, from which useful, new knowledge can be gathered. Unfortunately, most of it is not documented or inferences drawn.

Research in Developing Counties

A powerful tool to overcome the obstacles to better health in developing counties is research. But there are many obstacles.

- Personal: Intellectual isolation; low salaries; fewer career choices; insufficient training; attraction to affluent counties (emigration of researchers).
- Institutional: Insufficient access to information; inadequate support/technical staff; inadequate facilities.
- Environment: Lack of scientific culture; lack of demand for research; weak public support; bureaucratic rigidity; inadequate funds.

But it is necessary to develop essential national health research to

- understand the country’s pressing health problems;
- prioritize them;
- enhance the impact of the limited resources;
- improve health policy and management
- foster innovation and experimentation.

Research is often carried out in developing countries for the health problems of the rich counties. Various conditions prompt such researches; research costs are high in affluent establishments and clinical institutions are overloaded with research projects; there is strict application of ethical guidelines. Sponsors seeking fast and cheaper ways of carrying out the research turn to developing counties where the costs are lower, patients willing to participate in the research are plentiful and ethical principles are sometimes ignored.

Ethics and Research involving Human subjects

Research involving human subjects calls for the observance of ethical principles. Often these are violated. This is a matter of concern. These principles were initiated in 1964 by the World Medical Association in the Declaration of Helsinki which has undergone many modifications.

The major problems have been
• obtaining free, informed consent;
• withholding known effective treatment;
• use of children, mentally defectives and juvenile delinquents;
• drug induced toxicity – experiment continued;
• adverse effects and
• use of hazardous procedures.

It is necessary to carry out research on large populations e.g. in the study of vaccines. Ethical principles must be observed. Informed consent is often difficult because of illiteracy and other problems. But it is a must. Whenever possible, informed consent must be obtained from the individual subject and also from the community, involving community leaders

Certain important requirements stand out:
1. Free, voluntary informed consent. A mere statement (including the signature of the participant) has no meaning unless the subject or his/her guardian is capable of understanding what is being undertaken and unless all hazards are made clear.
2. An intelligent, informed, conscientious, compassionate, responsible researcher.
3. The gain anticipated from the experiments involving human subjects must be far greater than the risks involved.

Conclusion

Health research is a must. It is one of the most important driving forces for
• improving the health of the people and development;
• better performance of the health system;
• reducing the health gap between the rich and the poor and bringing about equity.

All people must be involved in health research. This would include the specialists (biomedical researchers, clinicians, epidemiologists, social and behavioral scientists, health economists) and all the people concerned with the health of the people. Peoples' participation is a must at all stages of research and particularly so in the assessment of the health impact on the application of the results of the research. Knowledge produced by health research is a public good. The benefits must be extended to all the people for the fullest attainment of health and development.