International Policies for Cancer Research: Report of a Conference on International Policy Approaches to Cancer Research (1981)

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INTERNATIONAL POLICIES FOR CANCER RESEARCH

Report of a Conference on International
Policy Approaches to Cancer Research

Sponsored by the Charles H. Revson Foundation

Prepared by Allyn M. Mortimer

Divisions of Health Promotion and Disease Prevention
and Health Sciences Policy

INSTITUTE OF MEDICINE

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This conference summary was developed by the staff of the Divisions of Health Sciences Policy and Health Promotion and Disease Prevention, Institute of Medicine, with the advice and assistance of the conference chairman, Dr. Arthur C. Upton. Conclusions and suggestions by conference participants on matters of policy are reported to assure completeness of the summary, but their inclusion does not represent policy statements by the Institute of Medicine.

The Institute of Medicine was chartered in 1970 by the National Academy of Sciences to enlist distinguished members of the appropriate professions in the examination of policy matters pertaining to the health of the public. In this, the Institute acts under both the Academy's 1863 congressional Charter responsibility to be adviser to the federal government and its own initiative in identifying issues of medical care, research, and education.

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INTRODUCTION

On June 30 and July 1, 1980, the Institute of Medicine held an invitational working conference on International Policy Approaches to Cancer Research.* The conference was held at the National Academy of Sciences in Washington DC, and was chaired by Arthur C. Upton. The conference was attended by representatives from several countries--the Netherlands, Egypt, Japan, the Federal Republic of Germany, England, Israel, Sweden, and the United States--as well as by representatives of international organizations, specifically, the International Agency for Research on Cancer (IARC) and the Pan American Health Organization (PAHO). United States participants included representatives of government, academia, public health, and clinical medicine. Appendix A contains a complete list of conference participants.

A list of questions was sent to the participants before the conference with the expectation that the questions would provide a common base for discussion. In addition, the questions served as the major foci for the conference agenda. Appendix B contains the list of questions, and the conference agenda. Selected background information provided by the conference participants is summarized in Appendix C. The discussion was divided into four topic areas:

- planning and organization of cancer research;
- resources for cancer research;

*This conference was one in a series of four conferences on Biomedical Research Policy sponsored by the Institute of Medicine's Division of Health Sciences Policy, and funded by the Charles H. Revson Foundation, Inc. The conference series was held during 1980.

- methods for stimulating innovation; and
- measurement and evaluation.

The discussion during the conference's first day concentrated on the first two areas, with special attention focused on ways decisions are made about the distribution of resources and the role of national government and non-governmental institutions in planning and implementing national cancer research policy. On the second day of the conference, the discussion on methods for stimulating innovation examined institutional and governmental policies for fostering innovative research. Discussion of measurement and evaluation examined ways information is collected in different countries and how these data collection methods can be improved.

PRELIMINARY REMARKS

The objectives of the conference briefly stated by Dr. Upton were:

- to review science policies in various nations and international organizations as reflected in policies regarding cancer research;
- to review how science priorities are established, how programs are organized and administered, how resources are allocated, and how training activities are planned and conducted;
- to identify common themes and issues and delineate points of disagreement; and
- to bring out needs and opportunities for international cooperation in cancer research.

Mr. Eli Evans, President of the Charles H. Revson Foundation, emphasized the importance of these conferences for the Foundation, because the exploration of biomedical research policy, particularly cancer research policy, is one of its major priorities. He also noted

that in the United States, the conference comes at a time of great public impatience and weariness with the large amount of money spent on cancer research. Mounting congressional criticism of cancer research, coupled with inflation and competing priorities, cause increasing difficulty in raising the necessary funds for government support of cancer research. These concerns were reinforced by Dr. David Hamburg, President of the Institute of Medicine, in his remarks during the second day of the conference. Dr. Hamburg stated that:

> The choices perhaps are more difficult than ever as we become aware of economic and other constraints in our own country and on a world-wide basis. So I believe very much that efforts at sharing information and ideas about science policy and other health matters ought to go regularly across national boundaries.

Dr. Joshua Lederberg, speaking as chairman of the President's Cancer Panel of the United States, reviewed a number of key issues in cancer research policy, both in the United States and within the international community:

- The organization of cancer research and treatment programs, for example, has been shaped to a large extent by our lack of understanding of the basic biological process of cancer.

- Yet, there are conflicting opinions about whether we should "wait to make" very large investments in admittedly imperfect service programs until we solve the biological problems.

- In the meantime, should we support basic research on cancer along a broad front even though it is impossible to predict which element of research will be most relevant? Is it realistic to target immediate research goals in a framework of limited knowledge?

- To accomplish our goals for investigation as well as prevention of cancer, a number of inspired, gifted, and motivated people are needed and have to be stably and adequately supported with less committee micromanagement of their creative initiative.

- Communication both among the scientific and clinical disciplines and to the public needs to be refined.

The public's perception of the possibilities and problems of major advances with respect to cancer cure and prevention needs to be translated into realistic and credible expectations for the future. Additionally, a personal effort should be made by people who are capable of educating the public with regard to the complexities of scientific issues. Investigators working at different levels of cancer research should also be brought into closer rapport.

Dr. John Higginson gave his perspective on international approaches to cancer research, as director of the International Agency for Research and Cancer (IARC), World Health Organization (WHO). In considering allocation of resources for research, he said, a balance must be struck between targeted research and the application of what we know we can accomplish at the present time, particularly preventive measures. The mix of research and preventive measures should be determined by national priorities, national resources, and by scientists who should attempt to maximize the output of the research effort. In a country where cancer causes only two or three percent of all deaths, for example, the national research program should be aimed at biological problems generally, of which cancer is a small part. He added that he believes the international health community should avoid doing research by routine simply because government regulations demand it--routine registration of cancer because other countries have cancer registries, routine testing of chemicals because other countries test chemicals, and routine regulation of carcinogenic agents. Such routine policies may make life easier for

legislators, but not make very good sense in the context of an individual country's pattern of morbidity and mortality, its total biological research program, or available scientific information.

Dr. K. Sune Bergström remarked that the World Health Organization does not have money for research in general, although it has mounted a great effort during the last decade to raise money for research on tropical diseases, human reproduction, and children's diarrheas--fields often neglected in the research programs of the developed world. The central WHO is not active in the cancer field at this time; most of the work is being done in Lyon under the auspices of the IARC. Nor is cancer research a priority of the WHO's Western Hemisphere branch, the Pan American Health Organization (PAHO). Dr. Jorge Litvak, chief of PAHO's Noncommunicable Disease Section, noted, however, that the regional offices of PAHO are seeking some extra budgetary support for collaborative cancer research by developing and developed countries.

Dr. Higginson added that each country, or group of countries, need not duplicate the research efforts of others, inasmuch as the results of cancer research in one country generally are applicable to another--as in the case of smoking-related cancer, for which there is a preventive measure. Ironically, United Nations' economic development funds are often used to finance the building of a new cigarette factory to bolster a country's economy . Thus, the lack of coordination of public policies that is seen at the national level in countries like the United States also is a problem internationally. (A description of factors affecting cancer control in developing countries was included in a paper provided

to conferees by Professor Mahmoud Mahfouz and is included in this report as Appendix D.)

PLANNING AND ORGANIZATION OF RESEARCH

After these preliminary remarks, the chairman turned the discussion to policy-making activities and the allocation of resources. Dr. Upton reiterated the dilemma posed by Dr. Lederberg that a balance must be achieved between basic or nontargeted research and categorical or targeted research. The amount of emphasis that should be placed on clinical trials versus screening for carcinogens in the environment, versus biological research related to cell growth, differentiation, and regulation is dependent ultimately upon public understanding, Dr. Upton believes, because politicians, who must appropriate funds for major research efforts, respond to their constituencies. Public misunderstanding about the state of research on cancer must be corrected in order to avoid excessive expectations in the future. The way in which the process of clarification is approached may differ from place to place and from time to time.

Mr. H. Voigtländer agreed that the legislators who control the budgets indeed make much research policy. However, a positive aspect of legislators' responding to media attention and constituent expectations regarding a particular cancer-related research program is that the program attracts financial and manpower support it otherwise might not, Dr. Leo Sachs noted.

Dr. Philip Schein said that in the United States, the National Cancer Act was probably oversold and that the public and members of Congress expected a major breakthrough in cancer research sooner than the cancer research system could deliver. In some instances, moreover, legislators and regulators who have supported cancer research and whose careers depend upon the success of that research exert specific pressure on investigators to justify their budgets for clinical and basic research. The problem, therefore, is to bring people to recognize that ideas, unlike programs, cannot necessarily be purchased with large sums of money. Additionally, he believes, the press and the public need to be aware that it may take eight to fifteen years to prove an idea or a treatment developed through research.

The distinction between fundamental and targeted research is the distinction between scientific problems that are soluble in principle and those that are simply waiting for an excellent idea, Dr. James Gowans said. In Great Britain, he continued, the mass media are only one of the forums where arguments may be made regarding the paths of scientific inquiry; the Parliament offers an alternative forum. Another way in which the public can express concern about cancer, he suggested, is through chairties. Two big cancer charities in Britain each contribute about $20 million annually to cancer research.

Dr. Theodor M. Fliedner of the Federal Republic of Germany reported that the competition for talent in society, particularly in industrial societies, is very keen because of the limited pool. The question of how to attract talented individuals to research careers is

very important. In the FRG, for example, the state government provides the basic support for all university departments not only for teaching but also for core research. A certain pool of money for basic research is available from the moment a person is appointed to a lifetime professorship at a university. He believed that both targeted and unspecified research are necessary, but the question of what fraction of total funds should go into each remains.

In the Netherlands, Dr. D.W. Van Bekkum noted, about two-thirds of cancer research is carried out in universities and is funded from university budgets. Decisions on research priorities are made by university departments, which are free to choose their own research objectives. One-third of the cancer research budget is provided by charity, most notably by the Queen Wilhelmina Foundation, through competition for grants. Since 1978, there has been a National Cancer Advisory Board in Holland, instituted by the government and charged with the responsibility of executing the national cancer program based on the U.S. model. The program involves comprehensive cancer centers and specialized cancer centers. The comprehensive centers are responsible for optimizing the fight against cancer by integrating scientific research with cancer prevention and treatment, as Dr. Higginson had suggested earlier. Health insurance institutions, which are part private and part socialized, assist in paying for three major aspects of the cancer centers--expert consultation to hospitals in the region, cancer registries (national registration of patients in hospitals in each region), and the basic administrative processes of the centers.

Elaborating on the system for support of cancer research in the United Kingdom, Dr. Gowans said that the immediate source of funding for the Medical Research Council (MRC) is the Department of Education and Science, which receives an annual science budget from Parliament. This allocation is divided among the five research councils on the basis of the proposals they present to an advisory board to the Department, which also promotes liaison among them. The MRC then allocates its share of the funds among three major activities: direct support for research teams in its own establishment; research grants to universities and similar institutions; and training awards. The Council has no precise strategy for the further division of funds for basic, prevention, and treatment research in cancer. Support for these categories of effort is provided in accordance with specific needs and opportunities identified periodically and on the basis of the merits of spontaneous applications for support in these areas.

Professor Bengt E. Gustafsson and Dr. Bergström noted that in Sweden money for cancer research is increasing because the public is interested in making contributions themselves, while funds for general medical research are lacking. Although Sweden's cancer registry has been supported by the government for a long time, cancer registries in other Scandinavian countries are in the hands of private cancer societies.

Dr. Frederick P. Li, a U.S. researcher who spent August through November of 1979 in the People's Republic of China, was asked to provide his observations on that nation's cancer research activities. He said cancer research efforts in China are divided among leading institutions

in the country; each center is responsible for research on one organ site. The Cancer Institute of the Chinese Academy of Medical Sciences, for example, coordinates studies of esophageal cancer, while the Tumor Institute in Shanghai coordinates liver cancer studies. Within each research institution, the research effort is multidisciplinary, although there appears to be relatively little long-term collaboration among institutions.

During the Cultural Revolution of the latter 1960s, Dr. Li continued, no funds were committed to training of research scientists, and research facilities deteriorated. Until recently, the main thrust of Chinese research was directed towards epidemiology, primarily because the more complex equipment necessary for laboratory studies was not available. But during the last several years, support for medical research has greatly increased, and a number of scientists are now pursuing advanced studies in the United States and Europe. In China, research, prevention, and treatment are in one support category. Efforts toward cancer control in China will probably continue toward understanding etiology by applying already existing knowledge and technology towards early detection. China has developed independently a comprehensive cancer atlas (similar to the U.S. county-by-county cancer maps developed by the National Cancer Institute) to show variations in cancer incidence, as well as atlases on fourteen other illnesses. Local cancer investigators--especially epidemiologists--are engaged in following up these geographic leads in hopes of finding prevention opportunities. Dr. Lester Breslow added that China now has two advantages in pursuing cancer research that it did not have ten to

fifteen years ago: the top leadership is no longer so strongly committed to cigarettes; and headway is being made with the epidemiological approach, as noted.

Dr. Takeshi Hirayama outlined the Japanese approach to resource allocation between biomedical research and other social programs. Although a certain proportion of the government research budget is roughly fixed, decisions on the remainder are usually made by judging the current status of public opinion. Decisions about the distribution of resources between cancer research and other biomedical research are made by taking into consideration the needs and demands for cancer control in the country. Specially organized committees of each government ministry make decisions about the distribution of resources among basic, prevention, and treatment research. The Ministry of Health and Welfare decided on five principal activities for cancer control in Japan: public education; screening and early detection by mass examination; improvement of diagnostic and therapeutic facilities; professional education and training; and promotion of cancer research. Mortality rates for cancers of the stomach and cervix, for example, have come down dramatically since the start of these control activities. Although cancer is the number one cause of death in Japan, there is no special national planning effort to make the most of the distribution of resources between cancer research and other biomedical research needs on a sound scientific basis.

In Israel, a cancer program in the usually accepted sense of the term does not exist, according to Dr. Sachs. Funds are allocated for the development of research, but nothing is specifically set aside for cancer

research. Major funding for cancer research in Israel has come from the U.S. National Institutes of Health through their International Research Program. In Latin American countries, cancer research should be one of the components of cancer control programs, and should be integrated within the general health services delivery system, thus approaching cancer control in a comprehensive way, Dr. Litvak, said. One of PAHO's key activities in this regard is to strengthen the cancer centers.

Professor Mahfouz commented that cancer research in the less developed countries (LDCs) is ad hoc at best, and that it is motivated by individual scientists. There is no formal allocation of funds for research, because national budgets are too small to meet much more basic needs, such as feeding the people, reconstructing the country, or developing the economy generally. Professor Mahfouz said that much of the money available for research is disguised in budgets for services. However, the principal resources for research usually come from bilateral or multilateral aid programs that are oriented toward supporting individual researchers (manpower-oriented). Basic research is undertaken in the universities as part of manpower development programs. In an attempt to coordinate, as well as maximize the nation's health research efforts, the Egyptian Academy of Sciences recently created a Medical Research Council. The new Council has chosen bladder cancer as its number one research priority.

In the Federal Republic of Germany (FRG), a national cancer plan would be very difficult to establish according to Mr. Voigtländer, because of the intricacies of their federal system. Comprehensive cancer

centers, however, do exist. Cancer research is sponsored in part by the federal government, in part by private organizations, such as industry. Within the federal system, decisions about the allocation of resources into cancer research as compared with other health needs depend on several factors--financial input, manpower, and the length of time it will probably take for some sort of results.

Dr. Upton briefly described the three kinds of cancer centers in the United States: comprehensive centers, which do both clinical and nonclinical research; specialized centers, which do only clinical research; and nonclinical centers, which do only basic biomedical research. Dr. Breslow commented on the role of cancer centers, based on his experiences with the center at the University of California at Los Angeles. In addition to providing the highest level of care for cancer patients, he believed that centers also should be concerned with preventive services and should bring together cancer research and public health policy. He suggested that a public health policy should be concerned with an appropriate balance between support of three aspects of cancer research: basic research, or trying to understand the biological mechanisms; clinical research to address the needs of cancer patients; and population-based or epidemiological research, trying to understand factors and conditions in people's lives that can be controlled to prevent cancer. The population-based approach, he continued, is not dependent on progress in the other research areas. Identifying and eliminating environmental factors, such as cigarette smoking or occupational exposures that can cause cancer, are examples of the

epidemiological approach. Although the balance among research efforts might shift over time, attention must be given to the prospects for progress in all three aspects of cancer research. Dr. Miller added that research advances can be made when laboratory research is combined with the epidemiologic approach; for example, in the clinical trials being done nationally and internationally, patients might be asked for such epidemiologic information as occupation.

What should be the role of the scientist with relation to social policy? As new risk factors for cancer are identified or implicated, legitimate scientific controversy about the interpretation of data frequently results. Dr. Upton noted that a scientist is expected to speak as a technical expert, to give the evidence and to give a scientific interpretation of the evidence; but ultimately, it is up to society at large to make the value judgments that must enter into any social policy or regulation. Constant international communication and coordination in some form is necessary to minimize the possibility of differing interpretation of the data. He believes that too frequently scientists have shied away from evidence that appeared to be fraught with controversy. Dr. Philip Schein concluded by reporting that in the past, scientists may have missed many opportunities--for example, in the United States, testifying before Congress about the detrimental effects of tobacco—to have an impact on government policies.

OPPORTUNITIES FOR INTERNATIONAL COOPERATION AND COORDINATION

Dr. Upton then commented on the interaction of cancer research in the United States with that of other nations. He noted that the number of scientists involved in U.S. cancer research has reached a plateau; and although the budget for cancer has dramatically increased, the total number of people being supported has increased less quickly. He identified three areas where the United States has helped to sustain activities in other countries: cooperation in clinical treatment where pooling of information and a large number of patients is critical (cooperative trials); epidemiological studies, where nature's experiments allow cooperative investigations to be par- ticularly valuable; and screening for carcinogens in the environment. The time-scale in which changes in cancer incidence may take place are being compressed, so that opportunities for international cooperation in epidemiologic research should be exploited.

Several international organizations were then described briefly by the participants. Dr. Van Bekkum said that the European Organization for Research on Treatment of Cancer (EORTC), after undergoing several changes in emphasis--from organizing multicenter clinical trials in chemotherapy to renewing interest in oncology--now is focusing on a strategy and policy for research on the treatment of cancer. A fellowship system has been established, and the EORTC sponsored numberous meetings and work- shops. Attempts also have been made to formalize and organize medical education and training. The most important function, however, is that

the EORTC provides a forum for individuals of similar interest and objectives, but with different backgrounds, to exchange information and keep abreast of recent developments.

Dr. Mirand described the function and activities of the International Union Against Cancer (UICC). The UICC is a nonprofit, international, non-governmental organization devoted to the advancement of scientific and medical knowledge in research, diagnosis, therapy and prevention of cancer and to promoting all other aspects of the campaign against cancer worldwide. It operates programs, for example, in the fields of cancer oncology, experimental oncology, epidemiology, and cancer education, as well as special projects, such as a recent one on smoking and cancer.

Dr. Gregory O'Conor mentioned that a new Program for International Chemical Safety was being established by the WHO to enhance cooperation in the areas of research, training, and information exchange relating to the problem of environmental chemicals. The benefits and problems of international bilateral agreements were then discussed. Dr. O'Conor believes that a principle advantage of bilateral agreements is that they represent a positive commitment of funds directed toward international cooperation in science.

Dr. Robert Miller said that it was easier to make progress in the research supported by some agreements than others. For example, in the United States/Japanese program, the cross-cultural differences in lymphocytic disease frequencies and their nature are being explored. Both countries in this instance are the beneficiaries of this program.

Dr. Gowans observed that international collaboration on clinical trials is problematic for several reasons, among them, the differences in health care systems. Moreover, the difficulty of obtaining compliance in domestic trials is much magnified in arranging for efficient multicenter clinical trials throughout Europe, for example.

Dr. Breslow identified four policy implications from the discussion thus far:

1. the need for technical development, including standardization of means of handling data, international statistics, and cancer registries;

2. a better understanding and exposition of the uses of epidemiologic data internationally to advance the fight against cancer and to guide prevention activities;

3. support for epidemiology in connection with research approaches and the training of research personnel; and

4. consideration of the active roles of government and industry with respect to cancer research and prevention

In this fourth area, the position of industry is problematic. There is the significant but largely undetermined role in cancer etiology played by occuptional exposures growing out of industrial work; there are cancer hazards arising from the products of industry (many of them quite profitable--for example, alcohol and cigarettes); and there is the growth and current extent of multi-national industries, which diffuses responsibility and decision-making at the national level.

There was general agreement among the participants that collaboration among disciplines--the basic sciences, clinical research, and epidemiology--is necessary. Furthermore, Dr. O'Conor thinks that a totally new approach needs to be taken with respect to the support of

epidemiology. He said that epidemiology is more than collecting statistics, more than doing case-control studies,* more than saying, "in this industry there is 1.6 times the expected rates of cancer"; rather, the development of hypotheses and hypotheses-testing should be emphasized. At present, an important policy issue--and one causing considerable public confusion--is that there is no way of proving a negative result from either an epidemiological point of view or from extrapolation from laboratory experiments, Dr. Higginson said. That is, the notion that a substance, carcinogenic at high doses in animals, is carcinogenic at low doses in animals or humans has not been amply demonstrated. Other difficulties in assessing carcinogenic effects (as well as other health effects) of environmental influences arise because of uncertainties about dose-effect relationships, the delay between exposure and resulting effects, and difficulties in extrapolating to humans from animal data. Variations in individual susceptibility also are just beginning to be understood. This, therefore, would justify investing a great deal of basic research to learn if we can extrapolate both nationally and internationally. Epidemiology's ability to direct a line of research, as well as the more usual approach of following up on an event, are two important features of the discipline.

*case-control study (retrospective): A study in which cases (i.e., diseased individuals) are selected and compared with controls (i.e., non-diseased individuals) to determine associations that might lead to identification of causes of disease.

METHODS OF STIMULATING INNOVATION

In many instances the United States' system of project grants tends to foster a reliance on activities for which there is a good prospect of payoff. Longshots, highly innovative, or imaginative work is not being encouraged to the degree that it might, U.S. participants agreed. Dr. Upton noted that under the system described an existing in the Federal Republic of Germany, for example, research money and technical assistance awarded to a tenured professor theoretically would allow for a degree of freedom and more daring investigation. The U.S. system could benefit from study of such arrangements, he believes. For example, perhaps funding criteria in the United States should focus on the investigator, rather than the short-term yield of specific proposals.

In an effort to follow up on these themes, Dr. Upton directed the discussion to the policies and principles underlying the approaches to long-range research innovation in various countries and regions of the world, given the ever-present fiscal constraints. The conference participants agreed that more secure patterns of funding and institutional arrangements were two elements necessary to foster innovative and creative research. This may explain why the policy of many European countries of providing long-term support to creative investigators appears to be successful, based on comments of conference participants.

In the United Kingdom's MRC, several additional conditions are considered necessary for a research system to be successful, Dr. Gowans said: the system must attract and recruit the brightest people, must

ensure a good flow of applicants even in hard times, must have a sound peer review system, and must meet the needs of the community. Approximately 60 percent of the budget of the MRC is spent in-house, supporting selected individuals who are given lifetime jobs and facilities to do full-time research; there are 60 such lifetime MRC units at present. They are established around gifted individuals or in response to a national need for research in such areas as toxicology, virology, or immunology.

Rigorous surveillance of the programs in place is also a necessary component of this system. If, after a period of time, researchers stagnate, the MRC may move them elsewhere within the system. If the unit as a whole falls below par, it is put on notice and if there is no improvement, the unit may be closed and the personnel dispersed to other units.

Furthermore, in the United Kingdom many young people are reluctant to take a short-term appointment or live on "soft money," opting for job security. Dr. Gowans' observation was supported by other participants, particularly as it affected those individuals who might want to take a position in another country but could not be assured of continued support in a research career when they returned home.

The research system in the Federal Republic of Germany, according to Dr. Fliedner, has two components--the university system and the Max Planck Society System. The latter is built around outstanding individuals who are appointed for life because of their leadership and innovative capabilities. Some young researchers who have originality but have never

attained leadership go on to careers in other systems, such as teaching. The university professorships in the FRG are supported by the state government and are usually given to those whose careers have evidenced a high degree of originality and attainment of leadership but with an emphasis on teaching.

Professor Gustafsson cited two programs--the International Cancer Research Technology Transfer Program and the International Cancer Research Exchange Workshop--in which Swedish researchers have participated that fostered an extremely useful exchange of ideas and new research techniques. But because of a curtailment in funding, these programs will not be supported by the Swedish government in the future.

An approach recently undertaken by the American Cancer Society (ACS) to provide support for young investigators is the establishment of ten Centers of Cancer Cause and Prevention Research. The director of each Center will have the responsibility for the long-term goals of the Center and ultimate decisions with respect to young investigators. Dr. Leffall also reported that the National Cancer Society Career Professorships are still being awarded.

Dr. Hirayama said that in Japan, academy meetings and workshops have proved very helpful in stimulating innovation and exchange of ideas. He said that over 90 percent of Japan's cancer researchers were trained in the United States, through the U.S.-Japanese Cooperative Cancer Research Program, which has scouted promising candidates.

Dr. Higginson noted that young investigators should be able to maintain a good deal of flexibility and should be able to move laterally

from discipline to discipline instead of being locked into a specific field. There should be some mechanisms established for any necessary retraining.

With respect to recruiting and retraining young investigators, Dr. Sachs said, first, every effort should be made to hire new research personnel each year despite financial constraints, and second, many young investigators are being attracted to alternative employment--especially industry--and are removing themselves from the university system in this way. Dr. Breslow pointed out that young investigators often suffer from "group dynamics" in research programs. He suggested that the contributions of young investigators often are stifled because of personality conflicts or the overpowering research interests of the principal investigator.

A National Science Foundation-sponsored effort was described that has engaged a network of universities and research institutes in a program to encourage high school and undergraduate university students to participate in research programs with the hope that because of this early exposure, they will ultimately pursue careers in science. Over 120,000 high school students have participated in the Student Science Training Program and from 50,000 to 60,000 undergraduate college students have taken advantage of the Undergraduate Research Participation Programs.

Dr. Van Bekkum pointed out several problems that were common among the conference participants that hinder innovation. Because of the international recession, there is an increased pressure on research budgets in general, including cancer research budgets. This puts more

pressure on researchers, especially young investigators, who have to devote much of their time to writing grant proposals that must be worded in such a way as to ensure funding. Not only does this divert their energies from their research, this general lack of security within the scientific community is detrimental to the continuation of innovative research. In Holland, moreover, there are many physicians waiting for specialty training, but while they are waiting they do not go into shaky research careers, they engage in other activities.

Dr. Irving London described the Massachusetts Institute of Technology Undergraduate Research Opportunities Program that so far has placed hundreds of students in research laboratories and facilities in the Boston area. He believes that the number of talented young people is growing, and those coming into scientific research are better qualified than ever before. He also described the Harvard-MIT Division Program that admits 25 students each year as candidates for the M.D. degree. Many of these students get their Ph.D. degree as well, and thus have the opportunity to pursue a collateral interest in research. One severe problem he noted is the lack of jobs for these first-rate graduates; many extremely talented people at the postdoctoral level, who should be out working on their own, have no place to go. This problem is especially acute for the Ph.D.-researcher. Professor Mahfouz noted that many of the same problems of a lack of career security for the young investigator exist in the developing world.

Dr. London suggested that the burden of illness should be examined in global terms when setting research priorities. With respect to the

distribution of research resources, Dr. Higginson pointed out that the LDCs were eager to have within their own boundaries more extensive tropical disease activities. In the long run, this could create within their countries an adequate base for future projects, including research on chronic diseases. Professor Mahfouz agreed and said that, for example, the immunological approach to most of the parasitic diseases is the same as that which could be applied to research on cancer.

DATA COLLECTION SYSTEMS AND PROGRAM EVALUATION

Dr. Upton next turned the discussion to the fourth point on the agenda, systems for data collection and program evaluation. With regard to the former, two main points were discussed by the conference participants: ways to link data systems and questions of privacy.

Systems for Data Collection

Dr. Van Bekkum noted that in the Netherlands the government's first priority is to establish a population-based cancer registry. But the problems of confidentiality and linking regional data on incidence to mortality data persist. Professor Gustafsson noted that in Scandinavia, every cancer case must be reported to the health authorities. Data from the doctor go to the central registry, then are distributed to three peripheral centers, one in Northern Sweden, one in Southern Sweden, andone in Stockholm. Aggregation of data in these regional centers provides a good opportunity for judging local differences in the occurence of cases. The information in the data banks is protected to reserve confidentiality, he said. The linking of data is easy because

everyone in Sweden is assigned a number, and all information on that person is computerized.

In the FRG, Mr. Voigtländer said, there is no legal obligation to report cancer cases, so no national cancer registry exists. Because of limited resources, the government relies on partial information systems; numerous problems arise in attempting to coordinate all these disparate systems and incomplete data banks. In the FRG at this time it is extremely difficult to obtain epidemiological data, because of stringent regulations on professional discretion and data protection, although a system of anonymous (by number) data for individuals is being suggested.

Dr. O'Conor described the U.S. Surveillance, Epidemiology, and End Results (SEER) Program, which is a project of the Biometry Branch of the National Cancer Institute. He emphasized that this program is not a national cancer registry, but a reflection of incidence data in eleven selected sites in the United States.* Among the primary objectives of the SEER program is the provision of detailed information on the incidence of, survival from, and mortality due to malignant neoplasms within the United States. Information is collected on anatomic site, histologic cell type, and extent of disease at the time of diagnosis of the cancer, demographic characteristics of the patient, how the diagnosis was established, the treatment given, and the subsequent survival of the

*U.S., Department of Health, Education, and Welfare, Public Health Service, National Institutes of Health, National Cancer Institute, Biometry Branch, Division of Cancer Cause and Prevention. SEER Program: Cancer Incidence and Mortality in the United States, 1973-1976. Young, Jr. J.L., A.J. Asire, and E.S. Pollack, Eds. DHEW Publication No. (NIH) 78-1837. Bethesda, Md.: National Cancer Institute, 1978.

patient. Dr. Breslow pointed out that the great limitation of the SEER program is that the data have not been fully exploited, and that they could serve as a resource for developing, quantifying, and affirming hypotheses about the etiology of cancer. He cited as an example of the potential usefulness of the SEER data its use in characterizing the 1970s upsurge of endometrial carcinoma in the United States. SEER program data identified the epidemic as limited to white women over age 50; further studies established the relationship of endometrial cancer in this population with the use of estrogens for menopausal symptoms.

Dr. Hirayama said that the 1979 epidemiologic data stratified by age, sex, and district are already available for Japan. In addition, occupation is recorded on selected cancer registries.

Dr. Bergström noted that many Swedish labor unions have central registries of the helath condition of their members. The building industry, for example, has a registry of 150,000 people. He hopes that these data eventually will be matched with data from hospital registries so that an occupational and environmental data base might be established.

Evaluation

In evaluating the effectiveness of research programs, the peer review system, as it has evolved throughout the world, appears to be of considerable importance. Dr. London, who served as a member of the National Cancer Advisory Board in the United States, commented at length on this system. He said that if an investigator-initiated project falls within traditional disciplinary lines, its quality will usually be

adjudged well; however, if it falls into an area between disciplines, it may have great difficulty getting a good evaluation. The system is simply not set up to evaluate multi-disciplinary projects well. The built-in rotation system for people serving on peer review panels also has a negative aspect. During the period when newly appointed people are learning the system, judgments that are not really valid may be made. For example, if the majority believe a project is good, and only one person disagrees, the project may be put into the class "approved but not funded." Despite these problems, the peer review system is the principal U.S. system for monitoring research quality and generally seems to work quite well. Over the years, the system has established credibility for the programs of the various Institutes of the NIH and has enabled the Congress and the people to be confident that funds for research have been invested wisely.

In the FRG, according to Dr. Fliedner, the German Research Society provides most of the funds for university-based research. Reviewers for investigator-initiated grant applications (single grants on the order of $50,000 to $150,000) are elected. Each two to three years every member of the faculty is permitted to vote for a reviewer so that for each field--for example, internal medicine, surgery, and so on--there are reviewers elected by the majority in their specialty. A small grant application is reviewed in writing by two people; the applicant does not know how these people are, but knows that they were elected by the scientific community for that specialty. The two reviewers submit their review to the chairman of the specialty section; the chairman makes the

final decision. If there is disagreement, a grant proposal may be sent to a fourth person for evaluation. For the past ten years, multi-disciplinary research groups located within university campuses have been operating in the FRG. (The funding level for these projects is approximately $500,000 to $1.5 million and involves 50 to 80 scientific workers.) Researchers in the groups whose proposals are being reviewed may suggest reviewers, and usually about half of these proposed reviewers are accepted. Reviewers make suggestions and specific recommendations on projects within the research area. In addition, experts from neighboring countries such as Holland and Switzerland are used as reviewers. With respect to review of clinical trials in cancer, the federal government has established a protocol review committee.

Dr. Hamburg asked for ideas and information about mechanisms for program evaluation, as contrasted with evaluation of individual projects. He observed that a line of inquiry may be exhausted, may be undermined by competing interests, or may be abandoned by investigators who go on to something else after a decade or so of fruitless research. He called attention to the need to understand the human element in the demise of a research project.

Dr. Schein was also concerned about the long-term stability of research programs and the fate of programs that do not seem to be producing results as quickly as they might. In evaluating any major research program, such as the National Cancer Program, responsibility to the individuals and institutions that have made commitments to it need to be taken into account. Perhaps programs should be allowed to change

emphasis rather than shut down. He noted that when programs are mandated by Congress, funds may be appropriated for a specific area of research without regard for the effects of shifting research emphasis. Serious disruptions may occur when funds are withdrawn from a meritorious program because an outside review body or a lobbying group has succeeded in having funds displaced to another area. Similarly, if new programs are mandated, a review must be made of their possible influence on existing programs.

Dr. O'Conor cautioned against over-evaluating and reprogramming too quickly. He believes that it is wrong to judge the success or failure of a program on whether it achieves a specific objective. Often, research results--especially basic research results--have useful applications well outside the context in which the projects that produced them were originally conceived. For example, Professor Mahfouz responded that the positive side of the U.S. "War on Cancer" should be presented to the public more aggressively. Dr. Sachs said the plan had extremely important implications, in that it represented an effort to mobilize a large sum of money to solve an undefined problem. He believes it was a pioneering effort, and one that should continue to be encouraged. Dr. Fliedner believes that the U.S. program tested a series of hypotheses, and that it is as important to know, for instance, that viruses do not cause all cancers as it would be to know that they do. He furthermore believes that the U.S. scientific community expected too much from the cancer program. Professor Bergström seemed to express the feelings of the non-U.S. participants when he said he is grateful for the NCI's

cancer program and believes it to have been an exceedingly worthwhile expenditure of national resources. Even though a "cure" for cancer has not been achieved, the work done under the auspices of the program has enabled substantial advances in biomedical research on a broad front.

Dr. Upton asked the participants how an assessment is made of the success, failure, or adequacy of the cancer research effort, particularly in countries that do not have a national cancer program. But, first, he asked Dr. London to comment on the responsibilities of the National Cancer Advisory Board in the United States. Dr. London said that the organization of the National Institutes of Health provides for a council for each of the institutes; the National Cancer Advisory Board serves as the council for the National Cancer Institute and the National Cancer Program. Its function is to maintain on ongoing evaluation of the overall program and the effectiveness of its principal constituents. The board can provide a valuable surveillance function, but sometimes it is more beneficial to have a disinterested group, like the National Academy of Sciences, examine various programs.

Mr. Voigtländer said that in the Federal Republic of Germany, the scientific advisory board is not restricted to reviewing only cancer research but assesses health research generally, The council is funded independently of research programs and is free to assess, monitor, and make proposals for the future, but has no institutional base nor special mechanisms of evaluation, which he views as unfortunate and hampering the council's potential effectiveness.

Dr. Van Bekkum said that in the Netherlands there is no specific

committee to oversee the cancer research effort, but that there are plans to establish a committee combining the efforts of scientists, public health professionals, and insurance organizations to review the cancer research program.

Professor Mahfouz noted that several factors need to be taken into consideration in program evaluation:

- The program's research results should be able to be transferred to specific, new procedures.
- There should be an upgrading in the health care delivery system.
- The research program should reflect the nation's health manpower development program.
- A positive social, economic, and political connection should result.

Dr. Breslow added that a scientific program such as cancer research could be evaluated from several directions. 1) Is the program meeting societal needs as viewed by society's leaders, primarily political leaders? 2) Is the scientific community enlisted in the enterprise? (In the U.S. cancer program, the scientific community certainly has been enlisted.) 3) Is the quality of the work high, as judged by the peer review system or some other quality assurance system? 4) Are solutions to important problems reached in the form of a consensus, and, further, can the scientific community come up with solutions to important problems? 5) Finally, is there honest and effective communication from the scientific enterprise back to the decision-makers or to the general public?

Dr. Miller pointed to another entirely different group who could contribute to the evaluation of scientists and their past research--

medical sociologists and historians. He noted the example of one U.S. medical sociologist who is beginning a study--reconstructed from interviews with leaders in cancer epidemiology in the 1960s--of the effect of epidemiologic research on leukemia upon the rest of cancer etiology during that decade. He believes the study of the evolution of ideas is worth pursuing, so that we can learn from the past how to place our efforts more effectively in the future.

SUMMARY OF MAJOR THEMES

- Public Understanding and Support for Research: Ideas versus Programs

Because research results can not always be purchased with large sums of money, it is important that public expectations of cancer research not be excessive, but be informed, realistic appraisals of the capabilities of science and the scientific community. Public misunderstanding about the state of research on cancer should be clarified because in the United States, as in many other countries, it is the legislators' response to the needs and concerns of their constituents that controls the research budgets and therefore the capacity of cancer research programs. (In Sweden, however, considerable monies are privately donated to cancer research because of widespread public interest.)

- Person versus Project Funding and Innovative Research

In many countries--the United Kingdom and the Federal Republic of Germany for example--support for research is built around exceptional individuals, who are in many cases sponsored for life. In the United

States, on the other hand, support for research is mostly program-oriented. The competiton for talent to do research versus other careers is very keen because of a limited pool of researchers, even in industrial societies. The ability of an academic research institution to attract talented individuals into research careers is of increasing importance. Some countries add a measure of security to this career choice by lifetime support.

Because of global economic constraints, many young people are not willing to take short-term appointments on "soft money", conferees stated, and are unwilling to take research assignments abroad that may put them behind the careers of their peers, instead opting for more secure posi- tions at home, often in private practice or with private corporations.

Does job security offer opportunities for innovative and creative research careers or stagnation? It is argued that freedom from the recurrent necessity of finding sources of support allows investigators to pursue innovative and creative avenues that they might otherwise not have time for or feel might not be funded. Institutional arrangements in some countries do not encourage longshots and highly imaginative work. However, the potential disadvantage is that security will encourage perfunctory performance. In England the quality of work of individuals is periodically surveyed (if a unit falls below par, for example, it may be closed and the individual workers moved to other locations within the Medical Research Council).

Other manpower concerns of conference participants included the lack of opportunities for extremely talented individuals; insuring a good

flow of applicants and the hiring of new personnel even in difficult financial times; and the maintenance of a sound peer review system. Several methods for promoting innovative research were suggested, including participating in academic workshops and meetings; allowing investigators to move laterally from one discipline to another instead of being locked into one career track; initiating and maintaining fellowship programs; and identifying students who are interested in science and offering them opportunities to continue this interest. (The U.S. National Science Foundation has sponsored several efforts that engaged a network of universities and research institutes in a program to encourage science research participation among high school and undergraduate college students. Because of this early exposure, it is hoped that they will ultimately pursue careers in science.) Another concern among the conference participants was that the contributions of young investigators are often stifled by the overpowering research interests of principal investigators.

- Opportunities for International Collaboration

Several areas were identified where collaboration among colleagues on an international basis would be highly desirable. These were: clinical treatment and pooling of patient material (cooperative trials); epidemiological studies; and screening for carcinogens in the environment. The consistent interpretation of scientific data and evidence from country to country was considered a goal worth striving for, which might be achieved in part by linked data systems and cooperatively developed cancer registries.

- Basic versus Targeted Research

Whether to have research programs targeted at cancer or whether to include cancer in the nation's overall biomedical research strategy varies widely among countries: research on cancer is very much targeted in the People's Republic of China where, for example, the Cancer Institute of the Chinese Academy of Medical Sciences coordinated studies of esophageal cancer, while the Tumor Institute in Shanghai coordinated liver cancer studies; in Israel, as in some Latin American countries, the nation's biomedical research program is not directed at specific diseases; in Japan decisions about the distribution of resources between cancer research and other areas of biomedical research are made by considering public opinion and national needs.

- Data Linkage and Registries

Although some countries, such as Sweden, have well established cancer registries, other countries, such as the Netherlands, are in the process of establishing them, and still other countries, such as the Federal Republic of Germany, have no national registries, and are unlikely to establish them. The United States does not have a national cancer registry, but instead has developed the Surveillance, Epidemiology, and End Results (SEER) Program, which is designed to reflect the incidence of cancer in the country. It is expected that this program will be increasingly used for a broad range of epidemiological studies related to etiology and specific aspects of cancer prevention. In Japan, a vital statistics system is well developed. Because of this system it is possible to trace the historical changes in cancer mortality in the

country. In the future, Sweden hopes to match data from hospitals having disease registries with that from occupational groups (the Swedish labor unions have central registries of members) and thus establish an occupational/environmental health data base.

- Privacy

Privacy and confidentiality were considered essential to the maintenance of a national health data system, but they are also impediments to an efficient system of linking and reporting national and regional health data. In Sweden confidentiality of information in data banks is protected, but information is easily collected and linked because everyone has an assigned number. In the Federal Republic of Germany, on the other hand, stringent regulations on professional discretion and data protection make it difficult to obtain epidemiologic data, although a system of assigning numbers to people in which individuals would remain anonymous is being suggested. In the United States, the implications of assignment of an identification number to each person have been discussed extensively, but at this time there are no plans for such a system because of privacy considerations.

- Peer Review and Evaluative Measures

Despite a few problems, the peer review system as it has developed throughout the world has been important in insuring high quality biomedical research. For federally funded research in the United States the system has gained congressional confidence, and it is believed that the system insures that tax dollars are being spent wisely. In the Federal Republic of Germany reviewers of investigator-initiated grant appli-

cations are elected by the majority of scientists in their specialty. In Germany the applicants attach great significance to the knowledge that their grants have been reviewed by persons elected by the scientific community. This is different from the United States, where selection of reviewers is done by a government process.

- Program Evaluation

In evaluating a specific research program, several questions were proposed: has the program resulted in the transfer of specific effective new procedures to practice? Is the program meeting societal needs? Is the quality of the work high? Has there been honest and effective communication from the scientific enterprise back to the decision-makers or to the general public? Is the history of scientific idea development (the evolution of ideas) worth pursuing, so that we can learn from the past how to place our current and future efforts more effectively?

Understanding the human element in many programs is extremely important. A commitment of funding should not be suddenly withdrawn because a program fails to achieve a prescribed goal. Changing the emphasis of a program might be a better alternative. A cautionary note--overevaluating a program or reprogramming too quickly may not be the most satisfactory solution when a program appears to be flagging. In the Netherlands there is no specific committee to oversee the cancer research effort; in the United States the National Cancer Advisory Board is charged with this function and provides an ongoing evaluation of programs and the effectiveness of its principal constituents.

APPENDIXES

A. Roster of Participants
B. Conference Agenda
   Questions for Participants

C. Summary of Selected Background Information
   Provided by Conference Participants

D. Cancer Control in Less Developed Countries:
   Factors Affecting Strategies and Policies
   by Professor M.M. Mahfouz

APPENDIX A

NATIONAL ACADEMY OF SCIENCES
INSTITUTE OF MEDICINE

Conference on International Policy Approaches
to Cancer Research

June 30 - July 1, 1980

Dr. Arthur C. Upton, Chairman
Professor and Chairman
Department of Environmental Medicine
New York University School of Medicine

EGYPT

Professor Mahmoud M. Mahfouz
Department of Radiation Oncology
and Nuclear Medicine
Cairo University

FEDERAL REPUBLIC OF GERMANY

Dr. Theodor M. Fliedner
Department of Clinical Physiology
University of Ulm

Mr. H. Voigtländer
International Relations Section
Federal Ministry for Youth,
Family Affairs, and Health
Bonn

GREAT BRITAIN

Professor James L. Gowans
Secretary of the Medical
Research Council
London

ISRAEL

Dr. Leo Sachs
Department of Genetics
The Weismann Institute of Science
Rehoboth

JAPAN

Dr. Takeshi Hirayama
Chief, Epidemiology Division
National Cancer Center
Research Institute

THE NETHERLANDS

Professor W. Hijmans
Laboratory for Pathology
University of Leiden

Dr. D. W. van Bekkum
Radiobiological Institute
Rijswijk

SWEDEN

Dr. K. Sune D. Bergström
Professor of Chemistry
Karolinska Institutet
Stockholm

Professor Bengt E. Gustafsson
Germ-Free Research Deparment
Faculty of Medicine
Karolinska Institute
Stockholm

INTERNATIONAL ORGANIZATIONS

Dr. John Higginson, Director
International Agency for
Research on Cancer
Lyon, France

Dr. Jorge Litvak
Chief, Noncommunicable Disease
Section
Pan American Health Organization
Washington DC

UNITED STATES

Dr. Lester Breslow
Dean, School of Public Health
University of California
at Los Angeles

Mr. Eli Evans
President
Charles H. Revson Foundation
New York NY

Dr. Joshua Lederberg
President
The Rockefeller University
New York NY

Dr. LaSalle D. Leffall, Jr.
Past President, American Cancer
Society
Professor and Chairman
Department of Surgery
Howard University College
of Medicine
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Dr. Frederick P. Li
Clinical Epidemiology Branch
National Cancer Institute
Boston MA

Dr. Irving London
Director, Harvard-MIT Division
of Health Sciences and
Technology
Cambridge MA

Dr. Robert W. Miller
Chief, Clinical Epidemiology
Branch
National Cancer Institute
National Institutes of Health
Bethesda MD

Dr. Edwin A. Mirand
Secretary-General of the 13th
International Cancer Conference
To be held in Seattle WA, 1982
Associate Director
Roswell Park Memorial Institute
Buffalo NY

Dr. Gregory T. O'Conor
Director, Division of Cancer
Cause and Prevention
National Cancer Institute
National Institutes of Health
Bethesda MD

Dr. Philip Schein
Profesor of Medicine and
Pharmacology
Georgetown University Hospital
Washington DC

National Academy of Sciences

Councilman Morgan, Executive Director
Assembly of Life Sciences

June Ewing, Staff Officer
USA National Committee for the
International Union Against
Cancer

Institute of Medicine

David A. Hamburg, President

Elena O. Nightingale, Senior Program
Officer and Acting Director,
Division of Health Sciences Policy

Vicki Weisfeld, Conference Coordinator

Allyn Mortimer, Research Assistant

Marcia Goldberg, Research Assistant

Sylvia Prince, Secretary to the Conference

APPENDIX B

NATIONAL ACADEMY OF SCIENCES
INSTITUTE OF MEDICINE

Conference On International Policy Approaches
to Cancer Research

June 30 - July 1, 1980

2101 Constitution Avenue NW, Room 280
Washington DC, U.S.A.

AGENDA

Monday, June 30, 1980

9:00 a m. -- Welcome and Opening Remarks, Dr. Arthur Upton, Conference Chairman

Topics for Discussion

- Planning and Organization of Research
- Resources for Cancer Research

12:30 p.m. -- Lunch, NAS Refectory

1:30 p.m. -- Discussion Resumes

5:30 p.m. -- Reception

6:30 p.m. -- Dinner for conference Participants, NAS Executive Dining Room

Tuesday, July 1, 1980

9:00 a.m. -- Discussion Begins

Topics for Discussion

- Methods of Stimulating Innovation
- Measurement and Evaluation

12:30 p.m. -- Lunch, NAS Refectory

1:30 p.m. -- Discussion Resumes

3:30 p.m. -- Conclusions and Recommendations for Further Efforts

4:30 p.m. -- Conference Adjourns

INSTITUTE OF MEDICINE

CONFERENCE ON INTERNATIONAL POLICY APPROACHES
TO CANCER RESEARCH

June 30-July 1, 1980
Washington, D.C.

QUESTIONS FOR PARTICIPANTS

1. Background Information

A. Please provide information about the epidemiology of cancer (incidence and/or mortality) in your nation

- by site
- by age and sex
- by other important population characteristic
- by calendar period (recent data; time trends, if noteworthy)

B. Please provide information about national trends in funding (government and private) for cancer research

- as compared to other kinds of biomedical research
- as a percentage of your country's gross national product or total health care costs
- by whether the funds were for basic research, for primary or secondary prevention research, or for treatment research, to the extent these distinctions can be made.

Do you consider this research investment adequate for your nation's needs, relative to competing priorities for funds?

2. Planning and Organization of Research

A. How are decisions made about the distribution of resources:

- between biomedical research and other social programs
- between cancer research and other biomedical research
- under the cancer research umbrella, among basic, prevention, and treatment research?

B. Is there a national planning effort to make some of the above determinations? If so, please describe.

C. What are the roles of the national government and nongovernmental institutions--including academic centers and industry--in planning and implementing national cancer research policy?

D. Do existing organizational arrangements promote or inhibit collaboration among different disciplines and among different institutions? How would you improve them?

3. Resources for Cancer Research

A. Are funds provided for the training of research scientists? If so, how many such researchers are supported and at what stages in their careers? How are the trainees selected, and is the method adequate?

B. Are funds provided for construction and renovation of research facilities? How are the funds allocated, and is the method satisfactory?

4. Methods of Stimulating Innovation

A. By what method are investigators and institutions selected for support? What are the advantages and disadvantages of this method with regard to stimulating creative research?

B. What policies have been developed to foster innovative research efforts? (including increasing the pool of young researchers, etc.)

C. Are steps being taken (other than any described in 2C) to promote interdisciplinary research? If more such efforts are needed, please describe.

5. Measurement and Evaluation

A. How is information collected about:

- the epidemiology of cancer
- treatment patterns and clinical advances
- known, suspected, and possible environmental carcinogens?

What are the strengths and weaknesses of the national data collection effort?

B. How are the efforts of the institutions conducting government-sponsored research monitored? In what ways would you like to improve the monitoring system?

APPENDIX C

SUMMARY OF SELECTED BACKGROUND INFORMATION PROVIDED BY CONFERENCE PARTICIPANTS

Data on international variations in cancer incidence and mortality provide the foundation for assessing differences in hereditary, environmental, and behavioral factors in cancer development. Variations in incidence or prevalence also enable generalizations to be made about the distribution of cancers world-wide[1] and provide clues to developing hypotheses about the etiology of cancer. For example, one generalization is that the world's poor and rich are at high risk for different kinds of cancer--except lung cancer associated with cigarette smoking--leading to the hypothesis that the dominant sites of gastrointestinal cancer may be determined by "nutritional economics."[2]

A changing epidemiological pattern of cancer can be observed as a country industrializes. In Japan, for example, there has been a rapid decrease in cervical cancer mortality and a steady decrease of stomach cancer mortality in both males and females. However, leukemia and cancers of the lung, colon, pancreas, breast, ovary, and prostate are on an upward trend. Similar patterns can be observed with morbidity rates. In the United States, likewise, the incidence of cancer of various sites for men and women, by race, have changed during the past decade. Men have more lung cancer, more cancer of the intestines, bladder, and stomach than do women, and have a higher overall cancer death rate.[3] Whites tend to have a higher rate than others of cancer of the breast, intestines, and bladder, but lower rates of cancer of the prostate, cervix, and stomach.[3] (See Table and Figure.)

In England and Wales the most frequently occurring cancers in 1973 were cancer of the digestive tract, trachea, bronchus, lung (decreasing in younger age groups), and breast. In 1978, in males, trachea, bronchus, and lung cancer resulted in a high mortality rate, while in females, breast cancer was responsible for the greatest number of deaths.

During 1975-1976 in the Netherlands, the average annual number of deaths from cancer was approximately 16,700 for men and 11,700 for women.[4] The incidence rate of malignant neoplasms of the respiratory system is far higher for men than for women.[4] Cancer of the digestive organs is frequent for both sexes in the Netherlands.

In many less developed countries, the magnitude of the effort at cancer control differs greatly from that put forth by industrialized countries. The effectiveness of any health care delivery system in controlling cancer is dependent on the adequacy and quality of resources, funds, manpower, health information and the record-keeping system, but the problems are even more complex in a developing country where a cancer control policy needs to be integrated with the dynamics of socioeconomic development. (See accompanying paper by Professor Mahfouz, Appendix D.)

In countries where cancer incidence and mortality are high, the expected level of funding for cancer research and control would be a proportional share of the total biomedical research budget. In Great Britain, for example, funds for cancer research are approximately 20 percent of the total medical research funding or 0.025 percent of the Gross National Product in 1979-80. Funding from three sources--the Medical Research Council, major national charities, and health depart-

ments--has been sufficient to support practically all research proposals of high scientific merit, and there are no indications that, overall, progress is being seriously hindered by funding problems.

In Egypt, funding for cancer research is provided mainly by the government as part of the usual department activities in the various university faculty departments related to oncological specialties. Private funding of research is not yet developed except for social activities, such as the Egyptian Cancer Society. Funding from bilateral or multilateral agreement resources is at present given to individuals rather than specific projects.

In Japan, funds for governmental cancer research in 1980 were $15,750,275 (or 3,780,066,000 Yen) and were provided by three ministries--the Ministry of Science and Technology, the Ministry of Health and Welfare, and the Ministry of Education. In 1979, Government support for the National Cancer Center Research Institute in Japan was an additional 872,248,000 Yen. Other research funds are provided by non-governmental organizations, such as the Japan Cancer Society (contributing 101,621,000 Yen in 1979) and the Society for Promotion of Cancer Research (contributing 61,000,000 Yen in 1979).

In the Netherlands, cancer expenditures are not adequate if compared to the proportion of cancer mortality to total mortality. Cancer research funding during 1977 was 13 percent of the nation's $320 to $360 million biomedical research budget and 0.014 percent of the gross national product. In the United States nearly $1.6 billion was obligated

during fiscal 1979 for cancer research and control. Of that, 59.3 percent was the budget of the National Cancer Institute.

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CANCER AROUND THE WORLD, 1972-1973

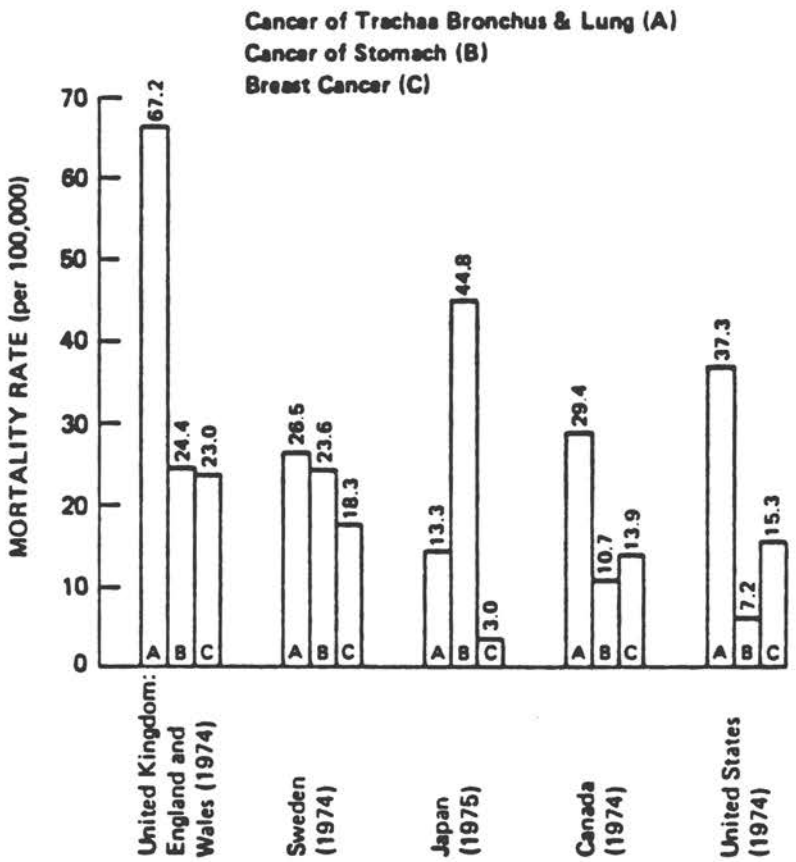
AGE-ADJUSTED DEATH RATES PER 100,000 POPULATION FOR SELECTED CANCER SITES FOR 44 COUNTRIES

Country	All Sites		Oral		Colon & Rectum		Lung		Breast	Uterus	Skin		Stomach		Prostate	Leukemia	
	Male	Female	Male	Female	Male	Female	Male	Female	Female	Female	Male	Female	Male	Female	Male	Male	Female
United States	157.2(22)	106.1(21)	4.6(10)	1.5(8)	18.9(17)	15.1(15)	48.9(9)	10.8(5)	22.4(12)	8.4(32)	2.4(10)	1.4(18)	7.5(40)	3.7(43)	14.4(11)	7.1(4)	4.3(15)
Australia	158.1(20)	100.0(26)	3.9(16)	1.3(13)	20.1(14)	17.4(8)	44.5(12)	6.7(14)	19.9(15)	7.7(35)	4.5(1)	2.6(1)	13.9(35)	7.0(38)	15.7(7)	6.7(10)	4.4(13)
Austria	191.1(5)	124.3(8)	4.0(15)	0.7(35)	23.9(2)	16.8(12)	52.3(7)	6.5(15)	19.2(17)	15.1(9)	2.2(12)	1.7(8)	33.2(8)	17.3(9)	14.3(12)	6.1(19)	4.3(18)
Bulgaria	128.2(28)	81.0(34)	1.6(38)	0.6(41)	8.6(30)	6.9(32)	36.2(22)	6.4(16)	11.2(29)	7.6(37)	1.7(21)	1.1(26)	31.0(11)	18.2(6)	6.3(35)	4.3(30)	3.5(26)
Canada	157.0(23)	109.4(19)	4.5(12)	1.4(10)	21.9(8)	18.2(7)	43.3(14)	8.0(10)	23.9(7)	8.0(34)	1.8(19)	1.3(21)	13.7(36)	6.3(40)	14.2(13)	7.0(6)	4.5(7)
Costa Rica	123.7(32)	111.2(17)	3.0(23)	0.8(29)	4.5(38)	5.1(37)	9.6(39)	4.3(29)	8.3(36)	18.2(4)	1.6(22)	0.7(35)	49.5(3)	30.1(3)	8.0(31)	3.9(35)	4.5(8)
Chile	157.8(21)	133.3(3)	2.5(31)	0.9(32)	7.8(32)	8.0(29)	18.5(31)	4.6(28)	12.2(26)	21.8(2)	1.1(32)	1.1(27)	57.4(2)	30.7(2)	11.5(23)	3.9(36)	3.3(28)
Czechoslovakia	204.1(2)	110.9(18)	3.3(18)	0.7(36)	21.4(11)	14.2(16)	62.9(6)	5.5(21)	8.6(35)	11.7(16)	2.4(8)	1.6(11)	33.5(7)	17.3(8)	10.1(26)	6.5(13)	4.4(11)
Denmark	170.2(15)	132.1(4)	2.1(35)	0.9(27)	23.1(5)	18.5(5)	46.4(10)	9.8(8)	26.3(4)	13.2(13)	2.6(6)	1.9(5)	16.4(30)	8.5(32)	13.4(17)	7.4(2)	4.9(1)
El Salvador	26.7(43)	42.7(42)	0.9(43)	0.3(43)	1.4(43)	1.6(42)	1.8(43)	0.6(44)	1.1(42)	6.5(39)	0.4(40)	0.2(42)	5.6(43)	10.1(25)	1.2(42)	2.9(40)	1.9(40)
England & Wales	184.3(8)	119.6(12)	2.8(29)	1.3(14)	21.7(10)	17.2(10)	73.5(2)	13.4(3)	27.1(3)	8.9(28)	1.6(23)	1.4(19)	17.5(27)	9.6(27)	11.8(22)	5.6(23)	3.5(
Finland	182.9(9)	99.1(27)	2.3(32)	0.9(28)	11.4(26)	10.4(24)	64.3(5)	4.1(32)	15.0(22)	7.3(38)	2.8(5)	1.6(12)	27.4(16)	14.1(16)	13.5(16)	7.0(5)	4.8(3)
France	187.0(6)	98.5(28)	13.4(2)	1.0(20)	20.3(12)	13.8(18)	33.6(24)	3.4(37)	17.9(19)	9.7(24)	1.5(27)	1.2(23)	16.6(29)	7.9(34)	14.8(9)	6.8(9)	4.4(10)
Germany, F. R.	178.0(12)	121.2(10)	2.2(33)	0.6(38)	22.4(7)	17.4(9)	46.0(11)	4.7(27)	19.7(16)	11.1(18)	1.8(18)	1.4(20)	28.7(15)	15.1(12)	15.0(8)	6.2(16)	4.4(12)
Greece	124.5(31)	75.3(38)	1.4(42)	0.5(42)	6.0(36)	5.5(35)	35.8(23)	6.0(17)	12.0(27)	6.0(40)	0.9(33)	1.0(30)	13.3(38)	7.8(35)	6.6(34)	6.9(7)	4.3(14)
Hong Kong	170.7(14)	98.8(29)	19.8(1)	7.0(1)	12.9(25)	8.7(27)	41.3(18)	20.0(1)	9.7(32)	9.8(23)	0.7(38)	0.6(37)	16.3(32)	9.1(28)	2.1(40)	3.2(38)	2.4(38)
Honduras	30.6(42)	45.9(41)	0.3(44)	0.1(44)	0.4(44)	0.2(44)	1.5(44)	0.8(43)	0.6(43)	8.4(30)	0.2(42)	0.1(43)	7.0(41)	6.6(39)	0.8(43)	1.6(43)	1.3(41)
Hungary	182.6(10)	125.6(7)	4.6(11)	0.9(24)	19.1(16)	15.5(14)	43.1(15)	8.2(9)	17.5(21)	16.8(7)	2.5(7)	2.0(4)	38.1(4)	18.6(5)	14.7(10)	6.2(15)	4.2(20)
Iceland	114.6(37)	93.8(30)	1.8(37)	2.7(2)	17.4(20)	9.3(25)	11.1(37)	7.4(11)	14.1(24)	5.9(41)	0.7(39)	2.0(3)	31.6(9)	14.9(13)	3.8(37)	4.9(28)	4.7(5)
Ireland	158.0(19)	122.1(9)	4.3(14)	1.8(7)	23.2(4)	19.1(4)	39.1(21)	11.9(4)	23.9(8)	7.7(36)	1.9(16)	1.7(10)	22.8(19)	13.8(17)	13.9(17)	6.2(18)	3.0(34)
Israel	121.5(33)	118.8(13)	1.5(40)	0.8(30)	13.1(24)	12.1(23)	23.1(28)	7.2(12)	25.2(5)	5.3(42)	1.2(31)	1.7(7)	15.7(33)	9.0(29)	7.5(32)	6.2(17)	4.3(16)
Italy	173.3(13)	103.0(23)	6.0(6)	1.0(21)	17.3(21)	12.8(21)	40.9(19)	5.1(25)	18.3(18)	11.2(17)	1.6(26)	1.0(31)	29.3(14)	14.2(15)	10.9(25)	6.9(8)	4.8(6)
Japan	141.2(25)	89.9(32)	1.5(39)	0.6(39)	10.1(28)	8.0(30)	17.7(32)	5.6(20)	4.6(41)	9.8(22)	0.8(36)	0.5(38)	59.6(1)	31.1(1)	2.1(39)	4.1(33)	3.1(31)
Luxembourg	200.7(3)	120.8(11)	6.2(5)	1.4(11)	23.1(6)	17.0(11)	64.5(4)	5.7(19)	21.1(13)	13.9(12)	2.3(11)	0.9(32)	21.6(21)	10.8(21)	13.6(15)	5.0(27)	3.3(29)
Mauritius	80.4(38)	57.4(40)	2.9(25)	0.8(31)	7.6(33)	4.4(39)	15.1(33)	2.2(41)	6.0(38)	16.4(8)	0.0(44)	0.3(40)	16.4(31)	7.1(37)	3.2(38)	2.3(42)	0.8(42)
Mexico	55.2(40)	71.0(39)	1.4(41)	0.6(37)	2.8(40)	3.3(40)	8.1(40)	4.2(30)	5.1(39)	18.8(3)	0.8(37)	0.7(34)	9.7(39)	8.6(31)	5.5(36)	2.5(41)	2.2(39)
Netherlands	186.9(7)	160.2(1)	2.0(36)	0.7(33)	18.4(18)	16.1(13)	67.5(3)	4.0(34)	29.9(1)	10.5(21)	1.7(20)	1.5(17)	22.0(20)	10.7(23)	22.9(1)	12.5(1)	4.3(17)
New Zealand	162.4(16)	114.4(15)	3.1(21)	1.2(16)	25.6(1)	20.8(1)	42.8(16)	10.2(6)	23.5(11)	8.6(29)	4.5(2)	2.2(2)	14.4(34)	6.2(41)	15.8(6)	6.6(12)	4.8(2)
Northern Ireland	159.8(17)	117.1(14)	3.3(17)	2.0(5)	21.8(9)	18.4(6)	50.7(8)	10.1(7)	23.7(10)	9.1(26)	1.3(29)	1.0(29)	20.1(24)	10.7(22)	11.0(24)	6.0(20)	4.0(23)
Norway	133.2(27)	101.4(25)	3.0(24)	0.9(26)	15.8(22)	13.0(19)	19.5(30)	4.1(33)	17.7(20)	8.2(33)	3.0(3)	1.6(13)	20.0(25)	10.0(26)	16.3(5)	6.4(14)	4.3(19)
Panama	75.4(39)	76.1(37)	3.1(20)	1.4(9)	4.3(39)	5.0(38)	11.0(38)	3.1(38)	6.6(37)	17.5(6)	0.3(41)	0.2(41)	13.5(37)	7.6(36)	8.7(28)	3.7(37)	2.4(37)
Philippines	49.8(41)	39.9(43)	4.4(13)	1.9(6)	2.8(41)	2.3(41)	5.2(41)	2.5(40)	4.7(40)	5.0(43)	0.8(35)	0.4(39)	6.0(42)	4.1(42)	1.4(41)	3.0(39)	2.6(36)
Poland	158.3(18)	102.9(24)	4.7(9)	1.0(22)	10.0(29)	8.1(28)	40.8(20)	5.1(24)	12.3(25)	14.2(11)	1.9(17)	1.6(15)	36.7(5)	15.6(11)	8.3(30)	5.5(24)	3.9(24)
Portugal	127.1(29)	91.1(31)	5.3(8)	1.0(19)	14.1(23)	12.9(20)	14.3(34)	3.1(39)	14.3(23)	12.3(15)	2.0(14)	1.6(16)	33.5(6)	19.0(4)	13.0(18)	5.8(21)	4.2(21)
Puerto Rico	119.5(35)	80.3(35)	10.2(3)	2.1(4)	7.2(34)	6.6(33)	14.2(35)	5.9(18)	8.8(34)	12.4(14)	0.9(34)	0.7(36)	19.0(26)	8.1(33)	12.6(19)	5.5(25)	3.3(27)
Romania	126.2(30)	146.5(2)	2.9(26)	1.0(23)	6.7(35)	6.3(34)	27.8(26)	5.4(22)	10.2(31)	17.9(5)	1.6(24)	1.2(24)	30.3(12)	13.6(18)	8.4(29)	4.6(29)	3.2(30)
Scotland	205.0(1)	128.4(6)	2.9(28)	1.3(12)	23.2(3)	19.4(2)	84.1(1)	16.0(2)	27.5(2)	8.4(31)	1.9(15)	1.7(6)	20.8(23)	11.7(19)	12.2(20)	5.3(26)	3.0(32)
Spain	137.4(26)	87.2(33)	3.2(19)	0.6(40)	10.2(27)	9.2(26)	24.4(27)	4.0(36)	11.4(28)	9.0(27)	1.3(30)	0.7(33)	26.2(17)	14.3(14)	11.9(21)	4.3(31)	3.4(20)
Sweden	114.7(24)	111.7(16)	2.7(30)	1.2(15)	18.4(19)	13.9(17)	22.6(29)	5.4(23)	20.2(14)	9.1(25)	2.4(9)	1.6(14)	17.2(28)	9.0(30)	21.1(2)	6.6(11)	4.7(4)
Switzerland	178.8(11)	108.7(20)	6.6(4)	0.9(25)	20.2(13)	12.8(22)	43.8(13)	4.2(31)	23.8(9)	10.7(19)	2.9(4)	1.7(9)	21.2(22)	10.6(24)	19.3(3)	7.1(3)	4.5(9)
Thailand	29.4(44)	19.6(44)	2.2(34)	1.1(18)	1.7(42)	1.2(43)	3.3(42)	1.3(42)	0.4(44)	3.0(44)	0.1(43)	0.0(44)	2.0(44)	0.9(44)	0.2(44)	0.4(44)	0.3(43)
Uruguay	200.6(4)	131.7(5)	5.8(7)	1.1(17)	19.5(15)	19.2(3)	42.6(17)	3.9(36)	24.0(6)	14.7(10)	2.1(13)	1.0(28)	31.4(10)	15.8(10)	17.6(4)	5.8(22)	4.2(22)
Venezuela	116.0(36)	104.0(22)	2.9(27)	2.5(3)	5.0(37)	5.4(36)	14.2(36)	6.8(13)	9.6(33)	25.5(1)	1.5(28)	1.1(25)	29.7(13)	17.7(7)	9.5(27)	4.0(34)	3.0(33)
Yugoslavia	120.4(34)	78.4(36)	3.1(22)	0.7(34)	8.4(31)	7.0(31)	30.1(25)	4.9(26)	10.3(30)	10.6(20)	1.6(25)	1.3(22)	23.0(18)	11.4(20)	7.4(33)	4.3(32)	3.0(35)

NOTE: Figures in parentheses are order of rank within site and sex group.

SOURCE: CA-A Cancer Journal for Clinicians. Volume 28, No. 1, January/February 1978, pp. 28-29. Based on World Health Statistics Annual 1972-1973.

Death Rates for Selected Causes, Various Nations.
(SOURCES: Infant Mortality--1976 Demographic Yearbook of the United Nations, 1977; All Others--World Health Statistics Annual, World Health Organization, 1977)



APPENDIX D

CANCER CONTROL IN LESS DEVELOPED COUNTRIES: FACTORS AFFECTING STRATEGIES AND POLICIES

BY

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CANCER CONTROL IN LESS DEVELOPED COUNTRIES:

FACTORS AFFECTING STRATEGIES AND POLICIES

By Prof. M.M. Mahfouz, F.R.C.R.

1. The main factors that affect cancer control are almost the same in any country, whether developed or less developed, but differ greatly in the magnitude of their effects on the combat of cancer.

   The presence of a national health policy, a national environmental protection policy, and a national research policy, and their effects and operational standards of the health care delivery system are the essential factors in the various degrees of success of cancer control.

   The delivery system's effectiveness is dependent on the adequacy and quality of resources, funds, manpower, health information and record-keeping system.

2. Socioeconomic Parameters of Underdevelopment:

   Although the features of underdevelopment are almost agreed upon among political scientists, yet, it is customary that the economic parameter is emphasized more than the social parameter in the process of comprehensive socioeconomic development in the Third World. Features of underdevelopment include:

   1) High rates of illiteracy.

   2) A low health profile, high infant mortality, high morbidity rates from infective and parasitic diseases, and malnutrition or under-nutrition.

   3) Low gross national product.

   4) Uncontrolled population growth.

   5) Environmental pollution is due mainly to individual behavior, as oriented and related to the existing value system.

   6) Inadequacy of systems of information and data recording, as well as operational administrative inefficiency.

   7) Lack of national planning capability and proper identification of development goals and, eventually, the incapability to maximize the benefits of aid programs.

The conceptual gap between economists and sociologists in their approaches to the problems of development in less developed countries (LDCs) has always led to emphasis on economic development, in the hope that it would rapidly solve the problems of those nations. This is in fact a short-sighted approach and always leads to detrimental social imbalances. Emphasis should be given to building up a system of information and a data base. Socioeconomic development has always been difficult and slow in most LDCs—this concept has to be accepted by both the donor and recipient of aid.

The building up of the developmental infrastructure, as well as the establishment of modern, effective operational and administrative machinery, are priorities and prerequisites for successful socioeconomic development. The presence or lack of these affects the efficiency and rate of development of any strategy or type of policy adopted by a country's administration--including those for cancer control services--as planning cannot be effective and maximization of time, efforts, and resources cannot be practiced without them.

Attitudes related to the value system, and political and ideological structures of societies, especially in the LDCs, sometimes lead to an emphasis on problems that have little developmental importance, but have a political or national prestige value. Such attitudes inhibit effective utilization of national and international resources for development. Furthermore, the over-sensitivity created by political, religious and ideological factors in LDCs can limit the effectiveness of technical and scientific advice, which impedes the proper utilization of available resources. Were the establishment of a viable and capable developmental infrastructure and the strengthening of operational and administration capabilities in LDCs recognized as prerequisite for international cooperation programs, such sensitivities could be logically overcome. Aid programs should incorporate such needs as a priority even if it is denied by the recipient.

3. <u>Prerequisites for Effective Cancer Control</u>:

3.1. That the cancer problem in the society gets into the perspective as a future major health problem whenever other existing important causes of mortality are controlled (e.g., parasitic, infective, and nutritional causes).

3.2 That a national health registry system is available. A cancer registry would be more easily established within a national system.

3.3 That the health administration and data-base health information system are sufficiently effective to lend their services to the problems of cancer control services.

3.4 That there is coordination with and a healthy involvement of the mass communications media in the process of disseminating information about health, population, and environmental protection policies.

3.5 That the medical and paramedical education programs take into consideration the importance of cancer as a forthcoming health problem.

4. Strategies for Cancer Control:

Important concepts suggest strategies for cancer control in any country. These are that cancer is a disease that can be prevented, treated, and cured, and its morbidity can be reduced. To achieve this, different strategies are needed in countries at different stages of socioeconomic development for the control of environmental pollution, for stimulating individual motivation to seek health care advice, and to assure an effective health care delivery system. In the developed countries, the major approach to cancer control is early detection, prompt, active and effective diagnosis, treatment, and rehabilitation, as well as emphasis on the contribution and the motivation of the individual to participate in that strategy and the strengthening of both basic and applied research. In the LDCs, early detection is difficult to practice; thus, the majority of cases are seen in the advanced stages of the disease. Therefore effective diagnosis and management are always both a humane and a psycho-depressive exercise.

Individual motivation for seeking medical advice cannot be relied upon in societies where illiteracy is common and inadequate health care delivery is the rule. Thus it stands to reason that if the available health personnel are oriented to SUSPECT the presence of neoplastic lesions and to refer patients to available medical services for prompt diagnosis, early detection may be more readily achieved. This strategy of cancer control depends on motivating available health manpower rather than on patients' personal motivation to seek early detection and management.

Strategies of cancer control in developed and less developed countries should always be integrated with policies regarding population and environmental pollution control.

A cancer control system has to be an integral part of the national health care delivery system, in order to economize on expenditures, neutralize professional jealousies and accommodate administrative sensitivities. The adoption of such basic principles will certainly affect policies relating to:

1) Medical and paramedical education.

2) The health care delivery system, family doctors, and health team activities in cancer control.

3) National health registration.

4) Establishing priorities for epidemiologic research and basic research and their relevance to national health problems.

5) International scientific cooperation.

6) National policies to control environmental pollution and population growth.

7) Health education policies.