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THE PRESIDENT'S MESSAGE

CANCER IN LOW- AND MIDDLE-INCOME COUNTRIES

by Ian Magrath

In 2010, cancer overtook ischaemic heart disease as the leading cause of death in the world. While different groupings of diseases (e.g., combining all cardiovascular disease or dividing cancer into many different types) would produce a different rank order, the point should not be missed that cancer can no longer be ignored by global health policy-makers as a major cause of disability or death, as well as economic loss.

In 2008, global economic loss resulting from disability or death from cancer, and not counting the costs of cancer control (the reduction of morbidity and mortality from cancer), was estimated to be US\$895 billion for the 17 types of cancer examined – higher than the cost of heart disease and sufficiently large that it can no longer be ignored by governments¹.

Yet cancer is a complex set of diseases requiring both public health experts and clinical care providers



Crowded children's ward at the Ocean Road Cancer Institute in Dar-es-Salaam, Tanzania.

and the participation of a broad range of institutions, ranging from government to academia and civil society, for its effective control. New approaches to creating concerted actions and developing the necessary finances need to be found. As such, the development of effective cancer control programs at a global level provides an enormous chal-

lenge, but also a unique opportunity to reshape the structure of health services in low- and middle-income countries (LMIC) as they grow and develop.

Unfortunately, the cancer burden in the LMIC, which has been growing steadily, has been largely neglected—by the governments of these countries, by international organizations

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and even by civil society. In contrast, considerable attention (appropriately) has been paid to HIV/AIDS, tuberculosis and malaria (the Global Fund to Fight AIDS, Tuberculosis and Malaria, for example, has committed, to date, US\$19 billion in 144 countries since its creation in 2002). No similar fund exists for cancer or even all non-communicable diseases combined, which are responsible for 60% of global deaths, although much could be accomplished with similar funding directed at non-communicable diseases in general and cancer in particular, the latter being the only potentially curable NCD.

Only in the last few years have a number of positive steps been taken to address the problem of cancer in developing countries: the International Network for Cancer Treatment and Research, dedicated to cancer in developing countries,



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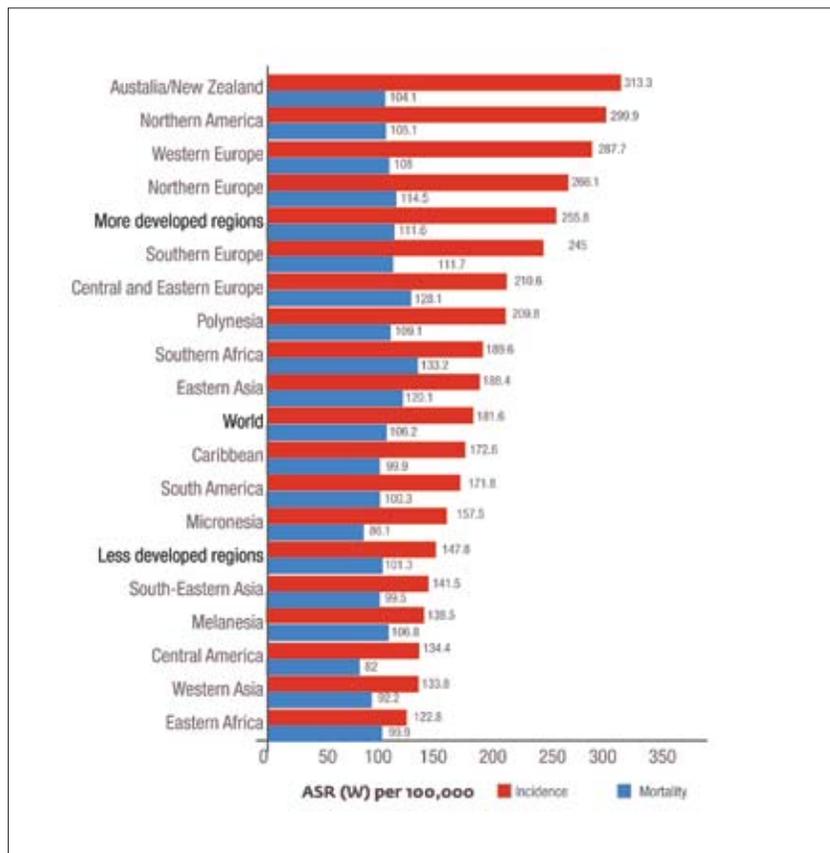


Figure 1. Age-standardized incidence and mortality rates in various world regions for all cancers except non-melanoma skin cancers; both sexes, all ages.

was established in 1998 to deal exclusively with this problem and has been supported by the National Cancer Institute, USA for the last 10 years; the International Atomic Energy Agency has long been providing radiotherapy units and training of the necessary health professionals in developing countries, but only in 2004, after recognition that radiation therapy alone is not enough, did it establish a broader Program for Action in Cancer Therapy.

Similarly, more than 50 years after the definitive recognition of the health risks engendered by tobacco, the Framework Convention on Tobacco Control, the first treaty negotiated by the World Health

Organization (WHO) and adopted by the World Health Assembly (WHA) in 2003, entered into force (2005). That same year, the WHA passed a resolution (WHA58.22) recommending that all countries develop comprehensive cancer control plans and budgets for their implementation. Finally, the WHO has recognized the importance of non-communicable diseases (NCDs) in general. In 2008 its NCD Action Plan was endorsed by the WHA, and at the UN General Assembly (UNGA) in 2010 on the Millennium Development Goals, Heads of State and Governments committed themselves to "a coordinated response to NCDs at national, regional and global levels."

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This will be further discussed at the High-Level Meeting at the UN General Assembly in 2011.

This article addresses some of the reasons that cancer – along with other NCDs – has become an important health priority in LMIC and why it does not command the attention that its contribution to disability and mortality rates (which are now similar across the world when corrected for the differing age structures of populations) demands (Figure 1). It provides basic information about the nature of cancer and its clinical features in order to inform the humanitarian argument for avoiding suffering from advanced cancer through prevention or early detection followed by efficient care (including palliation). It also discusses the need for international cooperation in creating the human and other resources needed to design and implement feasible cost-effective actions directed towards cancer control and to assist in the expansion and improvement of existing treatment facilities, thereby ensuring more rapid access to care.

Without such actions, mortality rates from cancer in the LMIC will reach catastrophic proportions with a resulting devastating effect on their economies. For success to be achieved, it is essential to dispel the notion that cancer in LMIC is an insoluble problem, and to encourage cancer control efforts in a systematic way as part of a global health initiative based on health priorities, not expediency. Present distortions and inadequacies in the health systems of the LMIC result in millions of cancer patients dying a sometimes slow and frequently painful, undignified death, scarring and negatively influencing the well being of their

families for life, and increasing the burden of suffering already predominantly carried by the 85% of people who live in the LMIC.

THE NATURE OF CANCER

Cancer, or neoplastic disease, (“new” growths or malignant tumors) results from the development of multiple genetic changes that, with occasional exceptions, occur after birth and are not heritable. These genetic abnormalities occur in a stepwise process in a single cell of almost any tissue or organ in the body and modify the behavior of the cell (and its progeny), creating precancerous lesions, some of which take on a “cancer phenotype,” which consists primarily of deregulated cell growth. Cancer cells proliferate inappropriately, forming masses or sheets of cells (they may also circulate in the bloodstream) that become progressively more able to invade adjacent tissues. At a variable point in its evolution, cancer disseminates, through a process known as metastasis, via

lymphatic vessels to regional lymph nodes and via the bloodstream to more distant bodily sites.

Leukemias and lymphomas are neoplastic “clones” of cells that occur in the bone marrow, spleen or lymph nodes. They can be generally considered to have spread widely throughout the body via the lymphatic system or blood stream, but can often be controlled for long periods, or even cured, by anticancer drugs.

In LMIC the incidence of cancer tends to be higher in urban regions, presumably a consequence of differences in lifestyle and/or environmental exposures. Cancer has a higher incidence in older individuals (above the age of 65 years), in part due to more prolonged exposure to environmental risk factors and in part, to biological reasons, such as the accumulation of genetic changes. However, cancer can occur at any age, and in LMIC accounts for a higher proportion of cancer because of the lower average age of

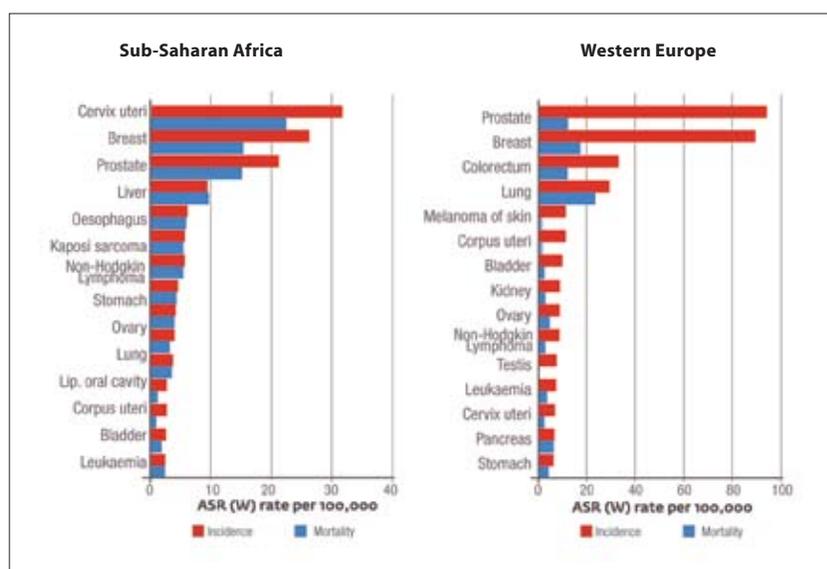


Figure 2. Age-standardized incidence and mortality rates for the highest ranked 15 cancers in Sub-Saharan Africa and Western Europe (both sexes).

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the population. For both reasons of population age structure, differences in lifestyles and environmental exposures, and, to a degree, ethnicity (i.e., different genetic make-up), the distribution of cancer subtypes varies quite markedly in different regions and countries (Figure 2).

In high-income countries, tobacco, overeating and a sedentary lifestyle are the major causes of cancer. In LMIC, chronic infections account for a higher, sometimes much higher, proportion of cancer. However, LMIC countries are faced with a low, but increasing burden of obesity, while still grappling, in the poorest of their people, with malnutrition.

There is much that can be done to control cancer, different cancers being more or less preventable or treatable (particularly in their early stages). Patients with incurable cancers should have access to palliative care.

PREVENTION AND EARLY DETECTION

Cancer prevention, of course, can only be accomplished if there is knowledge of the causal factors or predisposing causes for different types of cancer and the risk factors are such that environmental or behavioral changes designed to reduce risk can be promoted via legislation, the media, or via direct group or individual interventions in the context of the health system (including education and screening of the public), all of which require education and sometimes training of the appropriate sector of the community. This is not the case for all cancers, but it is important to note that some of those amenable to prevention (e.g., tobacco-related cancers), are often quite refractory to

Cancer control: A collaborative effort

Effective cancer control requires that all members of the community play their part – from practicing and promoting healthy behavior to detecting cancer early, and providing diagnostic, treatment and support services. International collaboration is essential.

The necessary communication among government departments, civil society and a broad range of health professionals will bring benefits to public health and health systems that go beyond cancer.

The cost of controlling cancer will be lessened by undertaking joint actions with agencies and organizations involved in the control of chronic diseases which share risk factors.

Specialists must be supported by a solid infrastructure and the necessary equipment, consumables, and personnel; strong links to primary and secondary care are essential.

Evidence should be collected by conducting research according to a prioritized research agenda.

treatment. Unfortunately, although legislation relevant to tobacco control, (the single most important approach to cancer prevention at a global level), has been passed in many countries, it is not always adhered to, or falls short of FTCT recommendations. Smoking rates are increasing in developing countries by 3-4% per year and women and adolescents are increasingly targeted. Approximately a billion of the world's estimated 1.4 billion smokers in 2010 live in developing countries, as do 70% of the 5.4 million who die each year from tobacco-related diseases². Much work needs to be done at the "grass roots" level to encourage smoking cessation, even though this will require a decade or two before it translates into a lowered incidence of smoking-related cancers. Discouraging the smoking habit entirely may be more readily accomplished, given sufficient effort,

in those countries or regions that still have relatively low proportions of smokers, since popular opposition to smoking bans will be minimal.

Cancers that occur in the context of chronic infections can also be prevented if vaccines or effective therapy exist for the infection. Vaccination against hepatitis B has been shown to reduce the incidence of hepatocellular carcinoma (liver cancer), and there is much hope that the new vaccines against some types of Human Papilloma Virus (HPV) will reduce the incidence of carcinoma of the cervix, 80% of which occurs in LMIC.

In the meantime, the screening of appropriately aged women for "in-situ" carcinoma of the cervix, which is easily treated with minimally toxic and very inexpensive therapy, has successfully reduced the incidence of invasive cancer at this site in technologically advanced coun-

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tries, and with sufficient upscaling and methodological changes, could reduce the incidence of this numerically most important disease in poor women in LMIC countries³.

The visual detection of leukoplakia has been shown capable of reducing the mortality from oral cancer in India⁴, but again, major upscaling will be required to have an impact at a population level. Simple screening methods requiring very little training, particularly if objective, are worthy of consideration in cancer control, but the consumption of skilled human resources in screening methods, e.g., for breast cancer, in LMIC countries is best avoided in the absence of good evidence of their utility and cost effectiveness. What little funding is available might best be spent on improving the education of primary care health workers and the public on the early signs of cancer, but early detection in the absence of facilities where patients can be diagnosed and treated effectively is an exercise in futility.

DIAGNOSIS AND TREATMENT

The first critical step in the management of cancer is to establish the diagnosis, which, with rare exceptions, is made after removing a piece of the tumor (or sometimes the entire tumor) and subjecting it to pathological examination. In the poorer countries or regions, and in circumstances where the patient must pay for diagnostic tests, modern and precise diagnostic methods may not be used, such that many patients are misdiagnosed and treated inappropriately.

Because of late diagnosis, however, a consequence of poor access to care for a variety of reasons addressed below, most patients have advanced

disease in such settings. Although figures of 60-80% advanced staged disease are often quoted for patients in LMIC, this will vary according to regionally available resources and other factors, and most figures are likely to be an underestimate because of inadequate staging (i.e., assessing the extent of disease).

Cancer is treated by one or more treatment modalities, i.e., surgery, radiation therapy or systemic therapy (chemotherapy, hormonal therapy or monoclonal antibody therapy).

Systemic therapy has been available only since the late 1940s.

The wider use of radiation and systemic therapy in cancer treatment has permitted the abandonment of most types of mutilating surgery (performed in an attempt to remove all cancer cells, including those that may have invaded adjacent tissue) although in many world regions, where radiation and systemic therapy are not accessible, or where fol-

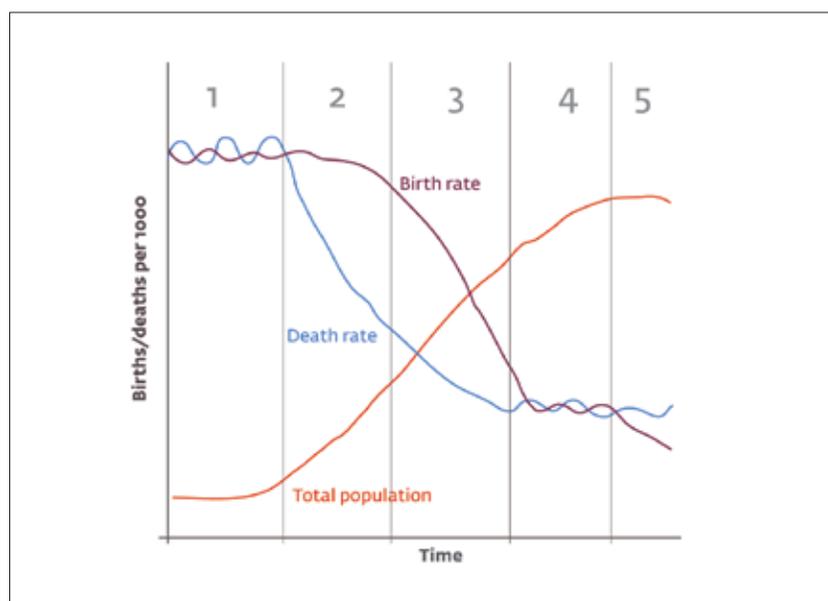


Figure 3. Diagrammatic depiction of the demographic transition that continues to disseminate across the world. Column 1 shows the situation prior to the industrial revolution. Most developing countries fall into columns 2 or 3.

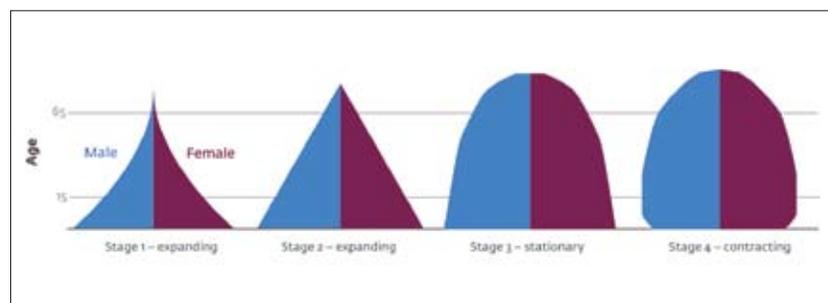


Figure 4. Population pyramids corresponding to the first four stages of the demographic transition shown in figure 3. Age is on the vertical axis, and relative numbers of individuals at each age are represented by the width of pyramid at that point.

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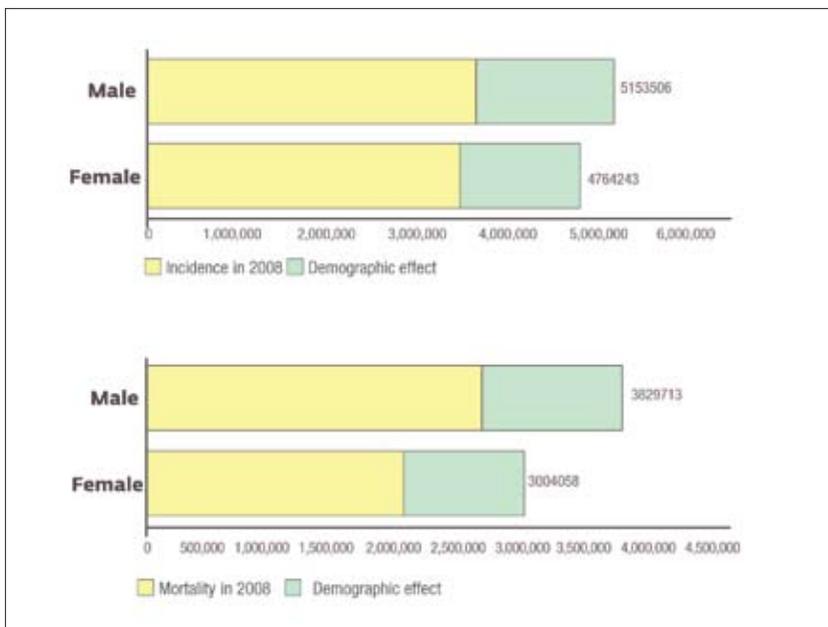


Figure 5. Predicted increase in number of annual incident cancer cases (upper graph) and annual deaths for males and females between 2008 and 2020, based on demographic changes alone.

low up is poor, mutilating surgery is often still performed on the grounds that it gives the poorest patients, who cannot afford additional treatment, or who may not return for follow-up therapy, the best chance for survival.

The greatest problem with radiation and systemic therapy is balancing the destruction of tumor cells with damage to normal cells. This is much more readily achieved with very early tumors – i.e., small tumors with no evidence of either significant regional involvement or distant spread when both cost and side effects are much less (although there is considerable inter-country variability).

Unfortunately, such localized tumors represent the minority of cancers in LMIC, in contrast to the situation in HIC. Moreover, patient compliance, whether due to cost issues, the difficulty of staying away

from home for long periods (travel to a specialized facility may be lengthy when few specialized facilities exist), social stigmata or a host of other issues, is often poor.

All of these factors contribute to the higher mortality rates in cancer in LMIC compared to those in HIC, but it must also be remembered that documentation of all aspects of care, and particularly outcome (because many patients are not adequately followed after treatment has been completed), also means that the quality of available information is often poor and published mortality rates probably give an overly optimistic view in LMIC.

PALLIATIVE CARE

A particularly sad aspect of cancer treatment in developing countries is the very limited access to palliative care. Of course, it is better to prevent or cure, but it will be many years

before the necessary steps can be taken to accomplish this. Meanwhile, symptom control is imperative to avoid suffering – throughout the patient’s clinical course, but especially when there are no curative options. Unfortunately, there is a paucity of information about the extent or quality of palliative care in the developing countries, although it is estimated that two-thirds of patients with cancer suffer from moderate to severe pain and few have access to pain relief. Palliative care is appropriately considered a human right; Human Rights Watch has equated the failure to provide physical and mental comfort to dying patients with cruel and degrading treatment – essentially, torture⁵. Oral morphine is inexpensive but grossly underused at a global level to treat pain, while psychosocial support is generally provided by the family, whose emotional suffering and lack of knowledge mean that not only are they poorly equipped for this task, especially in the absence of effective pain control, but they themselves are in need of support.

THE GROWTH OF POPULATIONS AND THE CANCER BURDEN

In recent history, the industrial revolution led eventually to increased living standards of ordinary people. Between 1800 and 2000, it is estimated that the world’s income increased ten-fold and the population over six-fold. As a result of this demographic transition (Figures 3 and 4), the global population reached one, two, four and six billion in 1825, 1930, 1975 and 1999, respectively. It is projected to reach 7 billion by late 2011 or 2012.

The demographic transition, result-

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ing in larger and, on average, older populations in less developed countries has markedly influenced both the burden and distribution of various cancers (and many other diseases) in various countries and regions. In fact, it has resulted in an epidemiological transition in which the major disease burden moves from communicable to non-communicable diseases. Unfortunately, as they make the transition, countries face high burdens of both, while their health systems remain adapted to dealing (however inadequately) with their prior health problems. An understanding of ongoing demographic changes permits predictions to be made with respect to the cancer burden in less developed countries based on demographic changes alone (Figure 5), or demographic changes plus an estimate of the additional numbers of cases that will be caused by other consequences of the industrial revolution, namely, increased exposure to risk factors such as smoking, obesity and a sedentary lifestyle (potentially offset by reductions in cancer related to chronic infections).

It should not be assumed that the burden of cancer will be confined to older people, whose risk of cancer is greater, but whose death or disability has a lesser impact. According to the IARC, the actual number of cancer cases in less developed world regions in individuals aged less than 65 years will increase by 3.3 million cases per year, compared to 3.9 million in patients of 65 or over between 2008 and 2020. This has significant economic implications, for even without considering the cost of treatment (and in low-income countries particularly, many patients may never receive therapy), the amount of disability and death

will have a significant negative economic impact on all countries.

RESOURCE DEFICIENCIES

The negative aspects of population growth must be offset by the technological benefits of the industrial revolution. Advances in healthcare that occurred resulted from research in an extraordinarily wide range of topics, but the spread of technical advances across the world has been both varied and slow. Even today, according to the IAEA, some 20 coun-

Widespread participation in clinical studies should help to improve the quality of services, since the research will provide relevant evidence while creating a scientific approach on the part of those responsible for determining national guidelines or actually caring for cancer patients.

tries lack radiation therapy entirely and many have a grossly insufficient number of machines (half of all radiotherapy machines are located in 15% of countries in the world!). Many radiotherapy machines are non-functional for lack of maintenance or require lengthy treatment durations because of an aged radiation source (cobalt machines). There are often shortages of radiation oncologists, technicians and radiation physicists – as well as severe deficiencies in a broad range of health professionals required to provide efficient care to cancer patients. Cancer drugs, even those on the WHO's essential drug list, may be available only intermit-

tently, and even if inexpensive by western standards, complete treatment courses may be beyond the means of many families.

The dramatic differences in resources for disease control, whether relating to prevention or treatment, between the LMIC, and HI, or OECD countries, cannot be emphasized enough. Those world regions with the smallest work forces of health workers and lowest expenditure on health (Africa and SE Asia) have the greatest disease burdens. Africa, for example, according to WHO, has 17% of the world's population, 2–3% of the global health work force, less than 1% of global health expenditure but approximately 25% of the global disease burden. Figures for the density of doctors and nurses (which vary by 7-8 fold) are available for most countries (Table 1) but information on numbers of specialists is largely lacking. In the poorer populations in the poorer countries there is essentially no access to even primary medical care, although traditional healers are likely to be available. Per capita government and total annual expenditure on health (US\$ at average exchange rate) approximately doubled between 2000 and 2007, but has an enormous span (several hundred fold) among countries grouped by income (Table 2). Moreover, there is gross maldistribution between urban and rural regions (Cote-d'Ivoire, an extreme example, had 2055 physicians in urban regions and none in rural regions in 2004). Insurance schemes are largely lacking in the poorer countries, where the bulk of health expenditure is private, out-of-pocket (Table 3).

Poor professional circumstances and the needs of high-income countries, coupled to higher salaries,

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	Doctors	Nurses and Midwives
Low-income	4	10
Lower-middle-income	10	14
Higher-middle-income	24	40
High-income	28	81

Data from World Health Statistics 2010, World Health Organization

Table 1. Doctors and nurses per 10,000 of the population.

	Government		Total	
	2000	2007	2000	2007
Low-income	5	11	14	27
Lower-middle-income	13	34	34	80
Upper-middle-income	115	269	221	488
High-income	1577	2699	2657	4405

Data from World Health Statistics 2010, World Health Organization

Table 2. Per capita government and total expenditure on health and at average exchange rate (US\$).

	Out-of-Pocket		Private Prepaid	
	2000	2007	2000	2007
Low-income	85.6	83.1	3.9	3.7
Lower-middle-income	92.8	90.5	2.5	5.3
Upper-middle-income	70.7	69.0	24.0	26.4
High-income	38.2	36.1	49.1	51.4

Data from World Health Statistics 2010, World Health Organization

Table 3. Out-of-pocket expenditure and private pre-paid insurance plans as a % of private expenditure on health.

encourage emigration (it has been estimated that 40% of African doctors are working abroad⁶) as well as entry into the private, for-profit sector which, as countries develop socio-

economically, evolves more rapidly than the public sector. This has meant that the growth of resources to control cancer at a global level has been much slower than the increase

in the cancer burden, leading to an ever-worsening plight of the cancer patient. The limitations in advanced human and physical resources are a combination of limitations in the economies of countries which ultimately stem from poverty, ill-health and inadequate educational systems – a triad of interacting problems that have implications at all levels of society. Without completion of primary education, for example, there can be no secondary or higher education.

CANCER AS A 21ST CENTURY GLOBAL HEALTH PROBLEM

Cancer has been progressively increasing in importance as a health problem since the industrial revolution, and particularly in the latter part of the 20th century, according to calculations based on available figures for the age standardized incidence rates of cancer for various countries in the world in 1974-57 and in 2008 (Table 4). Mortality rates, based on either cancer registry data or death certificates confirm this progressive increase which has been remarkably rapid in many LMIC, although cancer incidence also increased in the HIC in the latter half of the 20th century, particularly as a consequence of the tobacco epidemic, a more sedentary lifestyle and increased calorie consumption. It is also true, however, that due to education and the resultant earlier detection of cancer (in some cases, by screening e.g., for cancer of the cervix uteri), coupled to advances in treatment, there has been a progressive fall in cancer mortality. In the European Union countries (15), for example, between 1997 and 2004 mortality rates fell from 187.9 to 173.1 per 100,000 (standardized to a European population) (www.ec.europa.eu/health/indicators).

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Mortality rates, however, are generally rising in less developed countries due to increasing incidence rates resulting from the progressive adoption of a western lifestyle and urbanization. Unless cancer control can be dramatically improved, this will lead to an increase in the already large number of deaths from cancer in LMIC – perhaps reaching a total of 60-65 million between now and 2020.

According to IARC's Globocan, in 2008 there were 12.7 million incident cases of cancer and 7.6 million deaths, corresponding to age-standardized rates (adjusted to the structure of the world population) of 181.6 and 106.2 per 100,000 per year. It is predicted that in 2020, based on population growth alone (figures from the United Nations World

Population Prospects, 2008 revision), the number of cancer cases in the world will have risen to 16.9 million and the number of deaths to 10.2 million. The less developed countries will account for 2.8 million of these additional cases and 2 million of the additional deaths respectively – approximately 66% and 76% of the global increases (Figure 5). Already approximately 50% of both new cancer cases and cancer deaths each year occur in Asia and an additional 13% in Africa and Latin America combined (Figure 6). These predictions may be high or low, but given current Health G20 65 trends, there is no doubt that the cancer burden will increase in the next 10 years and that this increase will be both larger in the LMIC and result in an even higher fraction of cancer

deaths occurring in these countries because of their resource limitations. These same countries are also the most vulnerable to pressures from the commercial world designed to prevent them from enacting and enforcing legislation intended to reduce unhealthy behavior in their citizens, such as smoking and over-consumption.

An unknown number of patients in LMIC with overt cancer remain undiagnosed and untreated – for reasons ranging from wrong beliefs about the causes of cancer (e.g., evil spirits) and consequent stigmata, especially with genital cancers, to fear of cities where treatment facilities are located, ignorance, poverty or wrong advice (e.g., from traditional healers or local health workers). Others are diagnosed only when their cancer is advanced such that curative therapy is no longer an option, or would be costly and of low efficacy but high toxicity. The twin but associated problems of limited resources and late presentation result in high mortality rates, doubtless frequently leading to the misapprehension that there is nothing that can be done for cancer.

PROPOSED APPROACHES TO GLOBAL CANCER CONTROL

It is clear that cancer is a neglected health problem in LMIC. At the same time, there is a great deal of information about what can be done to control risk factors (often overlapping with risk factor control for other NCDs), detect cancer earlier, improve diagnosis and treatment, and provide palliative care, although not all of this information is directly applicable to the LMIC. This means that research into what works and what doesn't in

Country	1974-1975		2008	
	Males	Females	Males	Females
Austria	189	123	294	219
Belgium	200	115	357	276
France	195	99	361	255
Singapore	162	90	208	188
Japan	141	88	247	168
USA	159	106	335	274
Honduras	29	42	182	182
Mexico	58	74	134	126
Philippines	57	47	119	115
Puerto Rico	122	80	254	150
Thailand	34	25	146	156
Venezuela	101	100	150	158

Figures from ref. 8 and Globocan 2008

Table 4. Age-standardized incidence rates of cancer per 100,000 for all cancers (except non-melanoma skin cancers) in selected countries (hi top half of table, LMIC bottom half) in 1974-75 and in 2008.

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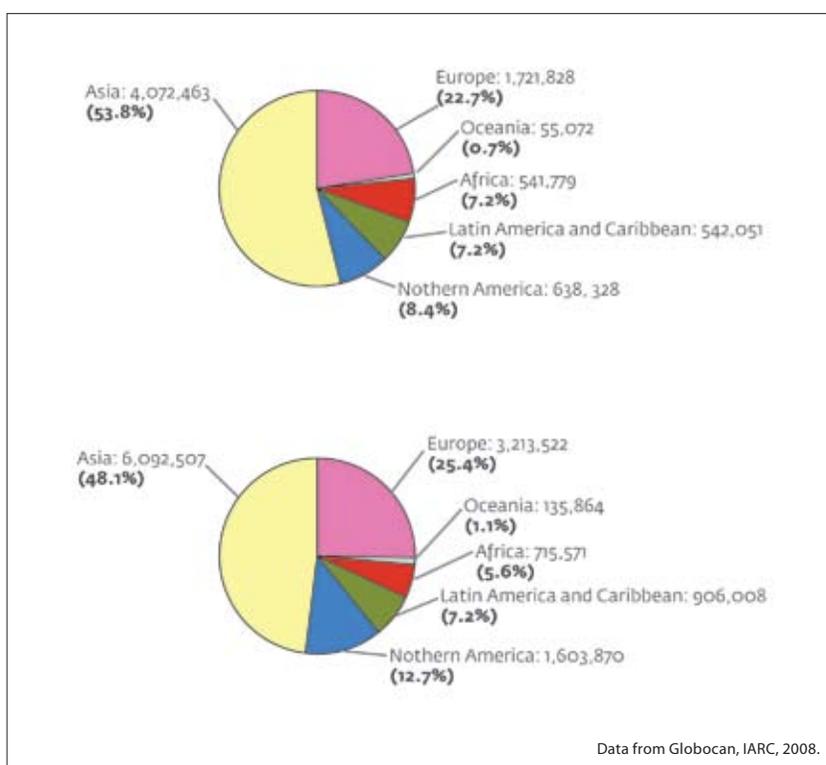


Figure 6. Distribution of new cancer cases (upper chart) and cancer deaths (lower chart) occurring each year by continent (both sexes and all ages).

LMIC must be given a high priority; frequently, specific actions may be inexpensive and highly cost-beneficial but their utility may vary from one country to another. Research will also create a more effective workforce, improve documentation essential to cancer control planning, allow an approach based on relevant evidence and increase the pace of progress.

Cancer registration is essential if the size of the cancer problem and the major types of cancer in different countries and regions are to be identified, and trends documented – thus enabling interventions to be prioritized, or the population impact of measures already put in place evaluated.

In determining what should be done in a given context, it is also

important to identify available resources, including facilities, equipment and human resources. Cancer control measures, for maximal effectiveness, will require the establishment of national and international networks to ensure the widest dissemination of expertise, whether in person or via telemedicine/e-learning of one kind or another. In addition to fully implementing the FCTC, decisions will need to be taken on the priority and resources required for the delivery of hepatitis B and HPV vaccines and the control of other chronic infections associated with cancer. Although still a relatively small problem in developing countries, the enactment of measures designed to minimize the obesity epidemic that has swept the high-income countries, bringing

with it serious health consequences, should also be given a high priority. Early detection should be integrated, wherever possible, with the early detection of other NCDs with similar risk factor profiles. This will require close collaboration among the various tiers of the health sector and begins in the community.

Approaches to improving access to care include such diverse issues as strengthening health systems, adapting them to NCDs and improving patient navigation. Insurance schemes, possibly initially covering only chronic diseases, as well as relevant public and professional education, must be planned and implemented. Continuing education of existing healthcare providers in a broad variety of professions should be undertaken, again, making maximal use of modern telecommunications as well as expertise from high-income countries, or, where feasible, from centers of excellence in-country or from other LMIC. It will be important that each country has at least one (depending upon size) focal point for comprehensive cancer control – i.e., a cancer center – which takes responsibility for the development and conduct of training programs as well as the organization of cancer services in the context of the overall health service structure, including the implementation of early detection, cancer diagnosis, treatment and palliative care at a regional level. This will generally be a component of the national cancer control plan (NCCP), and the latter should take into consideration anticipated increases in incident cases as well as changes in the pattern of cancer. Inherent to the NCCP this should be a national research agenda coupled to research training

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of at least a fraction of health providers and the development of the necessary infrastructure for research. Widespread participation in clinical studies should help to improve the quality of care, since the research will provide relevant evidence while creating a scientific approach on the part of those responsible for determining national guidelines or actually caring for cancer patients.

Treatment approaches should be adapted to available resources, including drugs, and cost. Expensive equipment, reagents or drugs may sometimes be cost-beneficial when they improve diagnosis or staging, permit patient throughput to be increased, toxicity reduced and, consequently, higher cure rates achieved, although maintenance and staffing must be included in decision-making. Rehabilitation programs for cancer survivors will greatly speed up return to work and contribution to the national economy.

It is clear that a set of diseases as complex as cancer require a team approach and participation by a wide range of individuals with both public health and clinical expertise as well as an intersectoral approach on the part of government. While the complexities and cost that this entails may seem daunting to policymakers and international organizations, such that much less attention is paid to cancer than its increasing importance as a health problem warrants, failure to address it effectively will result in a rising cancer burden continuing to outpace the growth of the resources required to address it and will have an increasingly negative impact on states' economies – in fact, with the cost of interventions daily increasing, this applies even in HIC. Novel

and effective solutions to the necessary restructuring of health services, health insurance, the education and training of medical and paramedical staff, task shifting (e.g., the use of medical assistants and training nurses to a higher level), the establishment of strategically located specialized centers that act as regional coordination sites for cancer control and interact fre-

(as was the case with lung cancer and smoking), clearly due to the problem reaching a threshold level such that it has become difficult to ignore. It is imperative that cancer is recognized by policymakers as the high priority health problem it has become in LMIC. Cooperation between and among LMIC and HIC is essential to lessen its ever-increasing impact, and there are lessons to

A global cancer control plan

Utilize the existing WHO regions and country offices as a geographical framework for global cancer control. Develop cancer control plans based on relevant research that can be “re-used” in countries with similar patterns of cancer and available resources, but anticipating future changes.

Emphasize education of all stake holders from policy-makers to primary healthcare providers and the public, with educational programs relevant to the implementation of cancer control programs in the local context.

Take advantage of cost-effective technologies that improve outcomes, including web-based applications for education and consultation.

Identify novel financial approaches, including insurance schemes, even if initially only for chronic diseases.

Establish centers of excellence which can form the focal points of local or national networks for selected priority programs.

quently and effectively with primary and secondary healthcare facilities must be identified within the briefest possible timeframe.

The identification of funds from national health budgets, international bodies, academic centers from high-income countries that can act as partners, and civil society will be essential to the rapid and effective implementation of selected cancer control measures. We have recently witnessed a number of calls to action in the context of addressing the problem of cancer in LMIC^{8,9}. This is

be learned by all. Necessary resources must be mobilized and joint efforts by governments, intergovernmental organizations, academic institutions and NGOs is essential. Discussing the problem is a beginning, but is not enough; immediate action is essential. ■

References available at www.inctr.org

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NETWORK

A DECADE OF INCTR: CHALLENGES AND OPPORTUNITIES

INCTR'S STRUCTURE AND STRATEGIES

BACKGROUND

INCTR was established in 1998 as an international not-for-profit organization (NGO) under Belgian law and dedicated to building capacity for cancer treatment and research in developing countries. Its founder members are the International Union Against Cancer (UICC) and the (former) Institute Pasteur. INCTR located its offices in Brussels, where activities commenced in April 2000. In March 2010 a special expanded Annual General Meeting was held to take stock of INCTR's strategies and activities. This report provides a brief overview of developments during this period as reported during the meeting.

From its small beginning, INCTR has developed to the point where it has branches or offices in ten countries (Canada, USA, Brazil, Cameroon, Egypt, India, Tanzania, UK, France and Nepal) in addition to its Head Offices in Belgium. This represents one component of its overall strategy – the continued enlargement of its international network. Secondly, since cancer is a complex set of diseases which require, for their control (reduction in morbidity and mortality), a broad range of both health workers and managers, INCTR has developed a series of organization-wide programs that cover various disciplines. At present there are seven programs. Five have existed for some time: Foundational

Programs, Clinical Research, Pathology, Pediatric Oncology and Palliative Care (PAX), while Cancer Registration and Cancer Nursing are in the process of being launched. A psychosocial program was discussed during the 2010 meeting and this will probably be initiated in the context of the pediatric oncology program.

New branches in Europe (e.g., Sweden) are being considered to expand INCTR's access to resources, and this is likely to be associated with the creation of new programs in adult oncology and cancer surgery and a considerable expansion of INCTR's ability to develop training and education programs, particularly in relationship to cancer treatment, although INCTR recognizes the importance of a combined public health/clinical care approach coupled to education of policy makers and the public.

INCTR'S MISSION, PHILOSOPHY AND STRATEGIES

INCTR's mission is to build capacity for cancer treatment and research with the vision of creating an international network dedicated to education and training and emphasizing a scientific approach. INCTR believes that working together with colleagues from developing countries "in the field" is the most efficient way to transfer knowledge to health professionals involved in the care of cancer patients. The latter are then in a position to educate their colleagues, particularly primary health care providers, who have a major role in ensuring that cancer is diagnosed as early as possible and that patients have access to existing treatment facilities.

INCTR's objectives are:

1. To build capacity for cancer treatment and research in countries with limited resources through long-term collaborative projects coupled to training and education.
2. To promote international collaboration directed towards cancer control between technologically advanced countries and countries with limited resources.
3. To take advantage of unique research opportunities.

The importance of research can never be underemphasized. It is essential if national priorities are to be addressed and relevant evidence in the local context created. It leads to a more analytical and disciplined approach to all aspects of health care. It allows advantage to be taken of unique scientific opportunities and will lead to greater independence of developing countries from high-income countries while playing a role in economic development.

In the creation of an international network, it was recognized that "local" ownership of programs and projects was essential, yet resources from high-income countries were necessary. Offices and branches in high income countries such as the USA, UK, France and Canada have access to regional and national resources that include both human and financial components. Offices and branches in LMIC provide regional or national coordination of INCTR programs and projects and participate in regional capacity building. The guiding principles of INCTR offices and branches are its Charter.



Participants at INCTR's 10th anniversary meeting in Brussels, Belgium.

DEVELOPING HUMAN CAPACITY

To achieve its mission INCTR must confront many challenges. While all countries have specialists and institutions dedicated to cancer care or who care for cancer patients, care in LMIC is rarely up to the standards of high-income countries. Minimal in-country research frequently results in ill-disciplined approaches to care and there is little or no surveillance of treatment quality. INCTR seeks to improve human resources within low- and middle-income countries (LMIC) for the delivery of effective care and recognizes the need for well trained specialists from the LMIC or high-income countries (HIC) to undertake this (although they need to be familiar with the challenges of cancer

care in resource-limited settings). Accordingly, it is in the process of developing an INCTR “faculty” from partnerships with academic institutions that is comprised of health care professionals representing a variety of disciplines required for the optimal delivery of cancer care. The INCTR “faculty” has performed on-site assessments, conducted training workshops and supported long term assignments of INCTR experts (months to years) to work with local staff at institutions in LMIC in order to provide training and education. Partnerships with academic institutions will enable INCTR to take advantage of their professional expertise in education, training and research and make it available to institutions in LMIC.

Standard training approaches are coupled to web-based approaches (e.g., e-learning, or the provision of on-line information as in the INCTR/MERLOT partnership (see p.24), which gives access to a broad variety of educational materials ([www.http://oerc.merlot.org/about/index.html](http://oerc.merlot.org/about/index.html)).

UP-SCALING

A strategy that INCTR strives to accomplish in the context of its projects “in the field” is to develop centers of excellence in care, education and research that can help spawn centers in other parts of the country or region. This should help convert small demonstration projects to interventions with a population impact – essential if a real difference

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is to be made to cancer control, and if that difference is to be sustainable. This does mean, however, that funding from within the country, or essentially permanent external funding, must be found. This is much more likely if an impact on national cancer control can be achieved and the success brought to the attention of policy makers and particularly ministries of health and finance.

INCTR PROGRAMS

INCTR identifies and initiates activities through its programs that are briefly described below.

FOUNDATIONAL PROGRAMS:

to create the necessary human resources and infrastructure to manage cancer treatment in LMIC.

CLINICAL RESEARCH

PROGRAM:

to develop the evidence on which to base interventions while providing care and training to health professionals.

PATHOLOGY PROGRAM:

to improve the accuracy of diagnosis essential to treatment and research.

PEDIATRIC ONCOLOGY

PROGRAM:

to ensure access to care for highly curable diseases in patients with a potentially long life span and to incorporate psychosocial support for patients and their families in the overall management of children with cancer.

PALLIATIVE CARE PROGRAM

(PAX):

to train health professionals in the provision of care in the context of regional training centers; to work with governmental authorities to improve opioid availability and to include palliative care in medical and nursing curricula.

CANCER REGISTRATION

PROGRAM:

to help develop a cancer registration program initially focused on Africa through the provision of necessary training and surveillance.

ONCOLOGY NURSING

PROGRAM:

to focus on training and education of oncology nurses.



A Panel Discussion: "Towards a Global Cancer Control Program" took place on the first day.

PARTNERSHIPS

INCTR partners with other organizations and institutions that have overlapping interests and activities. Partnerships may entail the joint conduct of projects and takes advantage of complementary skills or experience that exists in other organizations.

Because of its internal structure and the origin of its initial support as well as its ongoing support, INCTR has strong links with the National Cancer Institute (NCI) of the USA. It continues to extend its professional network with other governmental agencies, including the World Health Organization (WHO), the Program for Action for Cancer Therapy (PACT) of the International Atomic Energy Agency (IAEA), the European School of Oncology (ESO), MERLOT and other non-governmental organizations. It also works closely with university departments and seeks sponsorships and, occasionally, joint projects (although not product related) with the corporate world.

In 2010, INCTR was approved as a non-governmental organization in official relations with WHO.

EXAMPLES OF INCTR ACCOMPLISHMENTS

1. Treatment of acute lymphoblastic leukemia in India (four centers participated) with some 450 patients accrued.
2. A multinational (five countries) study for the treatment of Burkitt lymphoma in Africa (over 430 patients accrued to date).
3. Assessment of breast cancer care in four centers (Lima, Chennai, Lahore and Cairo) – over 8,800 questionnaires completed.
4. Assessment of pathology services



Prof. Guy de Thé (middle) received an INCTR Special Award for Exceptional Contributions to the Epidemiology of Virus-Associated Cancers (left, Prof. Jean Content, right, Dr. Ian Magrath).

in five sub-Saharan countries and development of plans for improving the quality of diagnosis. A telepathology program has been initiated.

5. Development of a palliative care center at MNJ Institute in Hyderabad, which provides patient care, training and education to health workers and works to improve access to opioids. Palliative care programs are ongoing in Nepal, Pakistan, Brazil and Tanzania and a reference Handbook has been published in print and online.

6. Collaborates with IARC in uterine cervical cancer screening programs in Tanzania and Nepal.

7. Assessment and accreditation of institutions in the management of clinical trials in Brazil (supported by Novartis Brazil).

8. Development of OERC (<http://oerc.merlot.org/>), an open access

resource for information about cancer, especially in LMIC, in collaboration with CTIS, MERLOT, Acrossworld and other organizations.

9. Education of the public (including school children) about cancer in Nepal.

10. Creation of bibliographies on publications from specific countries on specific cancers to identify volume and quality of scientific output, and help create a scientific approach in participating countries through training in quality assessment and systematic review and the identification of gaps in evidence. ■

*Melissa Adde and Ian Magrath
INCTR
Brussels, Belgium*

Selected discussions and working group reports from the 10th Anniversary Meeting follow.

NETWORK

PANEL DISCUSSION: TOWARDS A GLOBAL CANCER CONTROL PROGRAM

INTRODUCTION

Efforts to enhance cancer control in resource-constrained/challenged countries are currently conducted through a number of organizations at government, inter-governmental, non-government, academic, medical, industry, patient and civil society levels. Given that all such organizations and personnel share a common understanding of the need to enhance capacity building and knowledge transfer to improve population-based cancer control, the question of the value and possible structure of an "overarching" collaboration among these organizations to enhance achievement of common goals was discussed by invited panel members and delegates at the 10th Anniversary Meeting of INCTR in Brussels, March 2010.

DISCUSSION

A number of "rate limiting" challenges constrain initiatives to enhance cancer control. Among these, the most important are the funding required to implement programs and the challenges of recruitment and retention of committed personnel with appropriate skills in low and middle-income countries, given the abundant opportunities (and temptations) for trained personnel to emigrate and the lack of incentives to remain in their country of origin. Additional challenges include the lack of awareness of the need for population health approaches to cancer control, the mal-distribution of resources for the treatment of advanced disease, which are most

often available in urban but not in rural settings, the failure to appreciate the cultural and contextual conditions needed to align attitudes and approaches to interventions that can genuinely yield improvements in cancer control, and the frequent lack of resolve and political will to effect change. These challenges are



Dr. Simon Sutcliffe, President of INCTR Canada.

often compounded by the absence of a patient/public voice and the failure to engage civil society in promoting, through advocacy or direct participation, the improvement of health systems. The lack of coordination and coherence of various stakeholders groups, not to mention the humanitarian efforts of individuals, internal and external to the country being assisted, is also seen both as an impediment to progress, and as a source of potential confusion and duplication of effort that could be readily mitigated through increased collaboration.

Indeed, increased collaboration is a means whereby a number of constraints that presently hinder optimal actions could be addressed – by

ensuring focused, complementary goals across cancer organizations (and even other organizations, particularly those dealing with other non-communicable diseases), by taking advantage of synergies, such as addressing exposure to shared risk factors or the need for palliative care, and maximizing complementarities through shared planning, maximizing and optimizing strengths in various necessary elements of cancer control planning, implementation and evaluation, and leveraging resolve and political will through concerted engagement with policy makers. To date, at least some cancer organizations have established a good precedent for collaboration through agreement with respect to the needs in various resource settings and through "partnered" relationships in education, programmatic and service delivery in these same settings. There are, however, unrealized opportunities for further collaboration to overcome constraints through the creation of additional partnerships, e.g., with organizations concerned with HIV/AIDS, maternal and reproductive health, child health/infant mortality etc, and in recognizing the commonalities between the social determinants of health and environmental risk factors underlying both communicable diseases and chronic diseases. In addition, the promotion of linkages across governments, funding organizations and foundations, e.g., the Global Alliance for Vaccines and Immunization (GAVI) and the Global Access to Pain Relief Initiative (GAPRI), to simultaneously address health challenges related to infections, chronic diseases and cancer could present new opportunities for economy and synergy.

Collaboration is seen as a means to build and reinforce awareness of the need for cancer control at a population level with the simultaneous opportunity of influencing many widely accepted texts and bodies that, in turn, influence the actions of governments and major foundations alike, including the Millennium Development Goals, the World Cancer Declaration, and global political bodies such as G8/G20. It should create a coherent approach to resource acquisition and utilization; broader access to networks of people, knowledge and resources; shared information re: ideas, directions and priorities; complementary approaches to assist and support developing country agendas; and establishing common strategies to promote capacity building in cancer control.

When considering how collaboration could be enhanced, the priority must be given to what needs to be done, i.e., a functional rather than a structural (organizational) collaboration. The endeavor requires definition and alignment of strategic priorities and coherent approaches to implementation to ensure capacity to support key cancer control elements such as registries and capacity-building. The impact of interventions must be evaluated in order to ensure that the goal of incremental self-sufficiency and maintenance of a scientific, evidence-informed approach to population-based cancer control is being achieved.

Recommendations for action and direction in the context of global collaboration included:

- *The need to ensure that all stakeholders recognize the importance of cancer/NCDs* from medical, societal and economic perspectives on communities and countries. This

has implications for the collection of accurate incidence, mortality and survival data, and educational campaigns directed towards policy makers and the public.

- *One message, one voice* – the need for a combined approach to promulgate priorities and actions to enhance cancer control. Notwithstanding differing organizational governance, solutions for the global community require common, overlapping and reinforcing messages to influence political, medical and public resolve.

- *The overwhelming importance of prevention*, when possible, in the control of cancer and NCDs: tobacco use may be the single most important risk factor for NCDs, closely followed by diet and a sedentary lifestyle.

- *The engagement of new domains and forums*, e.g., NCDNet, the World Economic Forum, World Bank, etc. This will focus attention on the overall global health agenda, incorporating, but not focusing exclusively on cancer control, and is in line with the importance of NCDs as a major and growing global health problem, even in the low-income countries.

- *Finding synergies for action* within existing resource settings and ongoing programs and seeking support for new funding through combined, collaborative strategies both within and across cancer and NCDs.

- *A coalescence of focus on influencing global policy through incorporating cancer and NCDs into the wording of the MDGs*, recognizing that this will require a parallel process of demonstrating that cancer is preventable, treatable and sometimes curable, and the identification of channels to present the case for population-based cancer control at regional, national and global levels.

- *Learning lessons from effective strategies for other conditions/diseases* with substantial medical, social and economic consequences, e.g., HIV/AIDS. Particularly relevant are the comprehensive public health approach aligned with a medical intervention program, and the role of concerted civil engagement and societal resolve to address disease control.

CONCLUSION

Collaborative action between cancer control organizations presents an opportunity to define strategy, priorities, clarity of purpose, coherent and concerted influence at political, medical and public level, an optimized approach to human resource development and deployment, and rational use of assets and resources across the spectrum of cancer control. Avoidance of duplication of roles and activities would result in greater effectiveness with reduced confusion of purpose. Such collaboration among a broad range of organizations with very different motivations and areas of focus – governmental, intergovernmental, non-governmental, academic, philanthropic and private (including commercial) – could be achieved through focus on strategy and function without compromise of role or governance. However, appropriate forums for discussion and an inclusive approach on the part of lead organizations are essential if duplication, failure to grasp opportunities for complementation, failure to agree on priorities and opportunities to economize through joint action are to be avoided. ■

*Simon Sutcliffe
INCTR Canada
Vancouver, Canada*

NETWORK

REPORT ON EVOLUTION OF PATHOLOGY PROGRAM

DESCRIPTION OF THE PROGRAM

The program addresses issues related to diagnosis, education and research in pathology. The activities are focused on low- and middle-income countries, though the program involves experts and leaders in the field from a wide range of countries.



INCTR pathologists visit Cameroon.

GOALS OF THE PROGRAM

- 1) Improve standards of practice in cancer diagnostics among countries with limited resources.
- 2) Assist in improving the pathology infrastructure in countries with limited resources.
- 3) Develop networking of pathologists to optimize technology transfer and sharing of knowledge and expertise.
- 4) Develop pathology-based collaborative research projects between institutions with limited resources and institutions with better resources.
- 5) Explore opportunities to embed a pathology program within other programs and activities of the INCTR.

STRATEGIES TO ACHIEVE THE ABOVE GOALS

- a) Improvements in diagnosis will be achieved through workshops, updates and producing guidelines for pathology practice and the development of necessary datasets in countries with limited resources.
- b) Implementation of the pathology section of the INCTR program for "Online Diagnosis and Continuing Education in Pathology, Hematology and Oncology" using the iPath application developed at the University of Basel. Director of Program: N. Hurwitz. Director of Francophone Program: M. Raphael.
- c) Development of a robust second opinion or referral service for diagnostically difficult cases based, to the extent possible, on telepathology networks.
- d) Formation of a pathology research program sub-committee develop research studies and proposals, which would actively seek funding opportunities for collaborative research.

STRUCTURE OF THE PROGRAM

The program will have two Co-Directors, a program committee and a broad advisory panel or faculty.

PROGRAM COMMITTEE

Co-Directors

Manzoor Ahmed and Lorenzo Leoncini

Committee Members

Lorenzo Leoncini, Manzoor Ahmed, Nina Hurwitz, Martine Raphaël, Kikkeri Naresh, Shaheen Sayed

Advisors/Faculty

see below

Communication

Mostly through e-mails and conference calls. The committee will hold telephone conference calls on a monthly basis and meet in person once every four-six months.

PROGRESS AND PROSPECTS

Most of the goals are ongoing and need continued input. Annual reports will be prepared.

Achievements during the last year and targets for the next six months are detailed below:

- 1) Breast cancer reporting protocol drafted by Dr. Mazoor Ahmad.
- 2) Site visits to pathology laboratories in the last year: Lacor Hospital, Uganda; Kenyatta National Hospital and Aga Khan Hospital, Kenya; Muhimbili Hospital, Tanzania; Obafemi Awolowo University Teaching Hospitals Complex (OAUTHC), Ile-Ife, Nigeria; Ibadan University Hospital, Nigeria, and several pathology laboratories in Yaoundé, Cameroon. During these visits, INCTR pathologists identified problems and challenges to optimal pathology practice. A central review of lymphoma cases that have been entered into INCTR 03-06 protocol along with other cases not eligible for the protocol was undertaken. Discussions on the diagnosis of specific cases were held at each center visited. Following these visits, African colleagues have sent formal referrals of difficult cases to London, Sienna and Paris for second opinions, which have been provided.
- 3) Actions realized by the pathology section of the INCTR Program for "Online Consultation and Continuing Education in Pathology, Hematology and Clinical Oncology":
 - a. Pilot centers for telepathology have been established in Nairobi (local Director Jessie Githanga), Dar-es-Salaam (local Director Herbert Nguvumali), and Ile-Ife (local Director Kayode Adelusola).

b. An international INCTR Faculty for Pathology has been created, presently consisting of 40 members from ten Western and African countries covering all subspecialties in pathology. The scope of the involvement of the Faculty includes:

- i. Online consultations on cases in their fields of special interest.
- ii. Online support to improve histologic/cytologic techniques.
- iii. Performing special investigations not available in the laboratories of origin.
- iv. Support in introducing new methods (e.g., molecular techniques).
- v. Online case discussion and lectures; support in the preparation of publications.
- vi. Site visits (where feasible and funding is available).

Faculty Members will choose the degree of her/his involvement within the above mentioned activities. Two of the cases recently discussed in iPath will be presented at the Meeting of the Association of Pathologists from East, Central and Southern Africa (APECSA) in Kampala.

c. Several African centers suitable for the training of laboratory personnel in histologic and cytologic technique have been identified.

d. A Nigerian Federal Telemedicine Project has been launched in collaboration with the INCTR. In the first stage it will run in 55 tertiary hospitals. Coordinator: Dania Simpa, University of Ibadan.

4) We hope to initiate immunohistochemistry laboratories in three or four centers in Africa within the next year. Our intention is to develop centers within Africa that would be able



An informal discussion during the assessment visit to OAUTHC in Ile-Ife, Nigeria.

to train technologists and biomedical scientists from other centers in Africa.

5) A two-day meeting on lymphomas in Africa entitled "What we can Learn from Africa" was organized primarily by Lorenzo Leoncini with the help of the program committee and was held in Sienna during the first week of May 2010. There was large and active participation from African colleagues who presented cases from their centers that could not be diagnosed in Africa. Additional studies were performed and the diagnoses revisited with assistance of colleagues from Europe. In addition, summary lectures on the latest WHO classification of lymphomas and on the diagnosis of each lymphoma subtype were given.

6) An image gallery of common lymphomas in Africa along with a list of critical criteria for diagnosis was available during and after the Sienna meeting.

7) The INCTR supported by the International Academy of Pathology

is planning to hold an educational meeting in January 2011 for technicians and young pathologists in East Africa. This will include a three-day meeting in Dar-es-Salaam and a three-day meeting in Nairobi.

8) We would like to establish fellowship programs in pathology and will be seeking help from several granting agencies. Since the visit, one UICC/ICRETT fellow has been hosted in the University of Sienna in April 2010.

FUNDING APPROACHES

- 1) Capacity-building grants.
- 2) Research grants which would support infrastructure.
- 3) Educational grants to undertake visits and to hold educational meetings.
- 4) Grants to support fellowship programs.
- 5) Incorporation of pathology review programs within the INCTR's clinical research projects. ■

*Lorenzo Leoncini, Manzoor Ahmed, Nina Hurwitz, Martine Raphaël and Kikkeri Naresh
INCTR Pathology Program*

NETWORK

ONCOLOGY NURSING PROGRAM

GOALS

1. Discuss the goals and structure of the Oncology Nursing Educational and Advocacy Curriculum (ONEAC) program (consistent with INCTR's mission) and provide a brief description of both.
2. Decide on a Program Committee, how it will communicate and how often.

cancer patients in low- and middle-income countries (LMIC). This recently formed committee – the Oncology Nursing Education and Advocacy Committee (ONEAC) – has outlined a strategic approach to address identified needs for improving cancer education for nurses, particularly for those with no prior cancer training and for those with only “on-the-job” training gained by working with cancer patients. As is inherent in the com-



Eva Brun (left), Julia Challinor (middle) and Linda Krebs (right) chatting prior to the Oncology Nursing Program working session.

3. Decide on next steps with respect to development of the program and responsible persons.
4. Discuss possible funding mechanisms for the program and if possible, identify one or more funding strategies and who will implement them.

SUMMARY

INCTR's Oncology Nursing Program will be developed by a committee with “hands-on” experience in working with nurses caring for

mittee's name, advocacy for the role of the cancer nurse within the setting in which they practice will be part of the strategic approach, such that the role of the nurse is promoted and in some settings, expanded. The planned program takes into consideration the fact that even basic nursing education levels may differ substantially among developing countries. The overall goal of the program is to improve the delivery of quality cancer nursing care by focusing on

the needs identified by institutions as well as those identified through situational analyses of these institutions performed by ONEAC. Although any formal training will be tailored to the identified needs and culturally relevant, a core curriculum focused on the following content will be developed:

- The Principles of Cancer and Myths Surrounding Cancer
- The Continuum of Cancer Care
- Approaches to Cancer Treatment
- Safe Administration of Chemotherapy
- Aspects of Supportive Care
 - > Pain control
 - > Symptom control
 - > Infection control
 - > Nutritional support
 - > Late effects of cancer therapy
- Communication
 - > Patient and family education
 - > Psychosocial support
 - > Patient/Family counseling
- Spirituality
- Complementary and Alternative Medicine
- Basic Documentation of Care
- Nursing Ethics
- Nursing Leadership and Advocacy

Initially, training programs will be conducted in countries in which INCTR has collaborating units or ongoing programs. Nurses attending the program will receive a certificate for formal recognition of their participation and the program will be evaluated - both by the participants and by ONEAC's ongoing evaluation of program participants. ■

*Julia Challinor, Savitri Singh-Carlson, Sabine Perrier-Bonnet, Virginia LeBaron and Linda Krebs
INCTR Oncology Nursing Program*

PSYCHOSOCIAL PROGRAM

In order to ensure the importance of psychosocial support in the care and cure of the child and adolescent with cancer, Claudia Lancman Epelman From INCTR Brasil proposed the constitution of an INCTR Working Committee on Psychosocial Issues in Pediatric Oncology to promote a series of initiatives aiming at the integration of psychosocial intervention as a real part of the therapeutic strategy in Pediatric Oncology Centers.

BACKGROUND

The diagnosis of pediatric cancer is one of the most stressful situations a child or an adolescent and family will face. It presents an overwhelming series of stressors, not the least of which is the possibility of the patient's death. Although the survival rate for childhood cancer has improved significantly, the treat-

ments remain lengthy and intensive, involving fundamental changes in the patient and family's lives. Today, it is well known that a multidisciplinary approach to management should include psychosocial support services from the time of diagnosis to ensure maximum quality of life.

The provision of adequate information and the development of ongoing support will enable patients to grow and develop in preparation for entry into adult life, and to achieve their full potential. Psychosocial support should be an integral part of the total management of all patients.

Management of children and adolescents with cancer requires the participation of a multidisciplinary team – the physician working with other specialists: nursing staff, psychologist/psychiatrist, social worker, teachers, recreation specialists and members of different health care disciplines as the need arises.

Physicians should incorporate such consultations in the plan of treatment and, ideally, the multidisciplinary approach should be introduced in the routine of the patient immediately after the diagnosis is confirmed. Into practice, however,



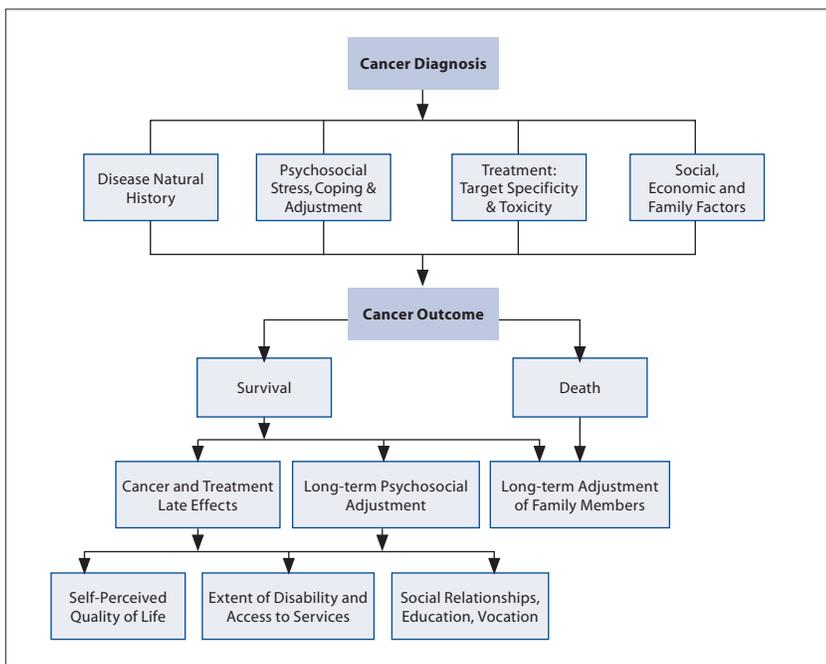
Claudia Lancman Epelman and Doug Ennals.

the multidisciplinary approach will become effective only through a carefully shared process in which all professionals perform their roles in a way that patient and family benefit from the interaction of all professional interventions.

THE MULTIDISCIPLINARY APPROACH

- Facilitates all necessary assistance to the patient and family, guarantees better adherence to the treatment and promotes the development of research;
- Determines the assistance needed to deal with the subjective dimension that the practice of modern medicine requires;
- Anticipates a perspective whose concept of health focuses not only on the absence of the disease, but also on quality of life.

Lack of a sophisticated psychosocial support structure in a hospital setting is not a reason to avoid or eliminate this crucial component of



Components of cancer diagnosis and outcomes and points of opportunity for psychosocial interventions.

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cancer care. In the absence of a dedicated professional, the physician in charge of the patient's care should be the leader. Health organizations and authorities should be sensitive to psychosocial issues in order to provide adequate resources to oncology centers in order to enable them to offer integral assistance to patients and families through multidisciplinary treatment. We have the responsibility to increase this discussion through the involvement of others in the multidisciplinary approach with the intent of integrating it into public health policy.

INITIATIVES

1. Prepare a survey to be mailed to all INCTR members to investigate the organization of the psychosocial intervention in collaborating Pediatric Oncology Centers in order to exchange information regarding the various types of psychosocial support programs that currently exist (or not) in various centers. One of the goals is to identify programs that could become models for emulation or imitation, which centers could promote training opportunities, etc.
2. Develop documents (guidelines, recommendations) for psychological and social management and support in Pediatric Oncology.
3. Propose collaborative studies.
4. Invite the participation of interested professionals.
5. Extend the program to adults. ■

*Claudia Lancman Epelman
and Doug Ennals
INCTR Psychosocial Program*

DEVELOPMENT OF AN INCTR FACULTY AND PARTNERSHIPS WITH UNIVERSITIES

Given that a major component of INCTR's work is education and training, a faculty of sufficient size, potentially involving partnerships with academic centers or professional societies, is required. The following observations were made by committee members:

- Experience has shown that there is a pool of talent interested in existing programs (e.g., pathology, palliative care, pediatric oncology) ready to undertake expert visits, assessment, and web-based case discussions, and assist in the implementation of solutions.
- Twinning (institutional partnerships) is a basic model to pursue, however, this program should be based on INCTR Teams, often from several centers rather than single individuals, should, in general, participate in the selected activities – predominantly training and education, but also clinical studies or advocacy relating to early detection of cancer. Several such programs have been initiated by the palliative care program, and multiple potential partners have come forward (Georgetown University, University of Lund, NCI, INCA, etc.).

FACULTY MEMBERS

The issue of faculty credentials was discussed. It was felt that appropriately qualified persons (e.g., oncologists, palliative care specialists) working at reputable institutions, particularly if well known to INCTR staff, would be eligible to be faculty members. Faculty will need, however, to be familiar with the problems of countries with limited resources, such

that their first visits should, in general, be undertaken with INCTR staff or faculty members already working in the country or region as a form of "orientation" and also to introduce them to INCTR associates working in collaborating centers in developing countries. It was recognized that Faculty should not necessarily be exclusively derived from high income countries (HIC); some well-trained and experienced persons working in low- and middle-income countries (LMIC) may have much – even more, due to their familiarity with resource-poor circumstances – to offer.

Since faculty members would have various amounts of time available, it was not felt that a minimal amount of time should be expected, although it would be useful to know how much time faculty would be able to commit – either as an online discussant or consultant, or in visiting one or more institutions in specific countries. Assessment visits might ideally be comprised of multiple experts.

Faculty members could be at various levels of seniority. The more junior members would be primarily engaged in teaching and education, the more senior may play an important role in developing strategies, e.g., relating to a specific project, or even to cancer control at a national level. Even medical students and trainees would benefit greatly from an international experience of this kind. INCTR has already organized visits of medical students, young physicians and nurses to various institutes it works with, particularly the Ocean Road Cancer Institute.

MECHANISMS AND INCENTIVES

A variety of mechanisms of donating time by faculty members could be envisioned. One might be a sabbatical period, another might be simply leave,

or unpaid leave. In the latter case a “consultation fee” may be required since it would not be fair to expect persons to lose income as a result of participating in the faculty.

Incentives to participate were felt to be essential and could include advantages in the pursuit of an academic career path insofar that faculty members would have a broader perspective and may engage in specific international research projects. At a personal level they would have opportunities to learn something of other cultures and other health systems. Persons interested in a career in international cancer control, e.g., with the United Nations or an NGO such as INCTR – an area of increasing importance likely, therefore, to require persons with international experience – would be in a better position to secure a desired post, or to be promoted as a consequence of their experience.

THE PROGRAM

INCTR will need to develop a more structured program that is well coordinated and focused on areas or disciplines already within the scope of existing INCTR programs (although new programmatic areas are anticipated to be developed as time goes by). The two major components would be actual visits, and participation in the development of training tools, whether for use in “hard copy” format or online. The latter might be well-constructed, comprehensive courses, or simply information, as for example INCTR and MERLOT have made freely available via the OERC program (see page 24). In addition, specific online case discussions as generally conducted in “tumor boards” or multidisciplinary meetings would be another format to be considered. This would also help orientate faculty members

who have not visited institutions in LMIC to the problems created by limited resources.

It was felt that bilateral exchanges, where trainees from LMIC spend time in institutions in HIC, held a significant risk of permanent migration of the participants for reasons of improved professional and personal circumstances.

Another discussion point was accreditation of specific competences. This could be performed by INCTR, or INCTR in conjunction with another organization or university. This is already ongoing in Brazil, where some 20 centers have been accredited by INCTR Brasil as competent to manage clinical trials.

Not only was it felt that this program is essential to INCTR’s evolution, but that it would bring added credibility and “branding” that would eventually be of great value to fundraising endeavors of many different kinds.

CEC - CANCER EXPERT CORPS - THE PEACE CORPS FOR CANCER

Dr. Norman Coleman presented a similar concept he has been working to establish for many years – in essence, a multinational corps of mentors. He would envisage INCTR being among programs CEC would support. He pointed out that while this was critical to organizations like INCTR working in the field, this kind of activity is generally not valued by most academic institutions or promotion committees in HIC, albeit, the issue goes well beyond cancer care and has implications for global collaboration and bilateral partnerships.

The goal of CEC is to mentor Associates-in-Training to a point where they are able to conduct protocol-based cancer care at a high standard. This would require the

development of multiple skills and talents, a high degree of motivation, adaptation to specific countries and would involve a range of health care providers, not just physicians.

For success, academic institutions would need to recognize the value of this kind of activity (or at least to accept it as a possible activity for staff



INCTR Faculty and Partnerships working session.

in periods when they are not required for patient care – as is the case for the University of Lund, for example. In addition, funding would need to be found, potentially via government to government agreements.

The project sequence was identified as 1. Needs assessment, 2. Establishment of goals and timeline, 3. Identification of the expert team (that may change as progress is made and needs change), 4. Metrics (measurement of progress) and 5. The development of independence in trainees who may then become mentors.

It was felt that INCTR could serve as a model and as a laboratory. Several of its programs, including pathology, pediatric cancer and palliative care, already have established programs of this kind. However, funding the needed expansion remains a problem. ■

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INCTR Faculty & Partnerships Program*

NETWORK

OPEN EDUCATIONAL RESOURCES FOR CANCER (OERC): TWO YEARS OF PROGRESS

OERC RATIONALE

The rapid rise in global cancer rates is well established as discussed in the President's Message. By 2030 estimates from The International Agency for Research on Cancer indicate that in the absence of improved cancer control, the global burden of cancer could be as high as 17 million new cases per annum. Already, more than 50% of cancer cases and 70% of cancer deaths occur in developing countries.

levels, and it is generally agreed that human capital development - the expansion and education of the cancer workforce - is a critical factor in ensuring progress.

The need for education in cancer care was a major factor in the decision to develop OERC. At the same time it was evident that extensive cancer educational materials are continuously generated by teachers in universities, cancer institutes, professional organizations, national and international, and non-governmental, not-for-profit organizations. Many excellent didactic modules covering a broad range of cancer-related topics remained unpublished and inaccessible in the public domain. Thus it was proposed that learning modules of varying formats, but with a particular emphasis on topics relevant to low- and middle-income countries, be solicited, reviewed, classified and collected in an open resource repository accessible, via the Web, from anywhere in the world.

OERC - THE FIRST TWO YEARS

In June of 2008, at the American Society for Clinical Oncology meeting in Chicago, 30 cancer educators and researchers from INCTR, NCI and various universities gathered for a day to enhance their understanding of the educational requirements to build capacity for cancer control in developing countries and to develop a mechanism for global sharing of cancer educational tools. A small, interdisciplinary working group of committed individuals (later to become the OERC Executive Committee) began to design an online repository of cancer education modules selected to aid educators in low-resource countries to



Open Educational Resources for Cancer

develop curricula and teaching programs tailored to the specific needs of their learners and local environment. Materials were searched and solicited from a wide range of sources, in order to be made easily accessible via a Web Portal at no cost to medical teachers - anywhere and at any time. In 2009, a mission statement was formulated by the Executive Committee as follows:

- To enhance knowledge sharing among countries on cancer control strategies
- To expand the capacity of physicians, nurses and care givers in developing countries to treat cancer patients
- To make available cutting edge research information on cancer care in an easily accessible format at no cost on a worldwide scale
- To make available the latest clinical trials information to cancer care providers and patients
- To act on the current WHO recommendation for knowledge sharing and cancer control
- To contribute to the development of a research infrastructure and a research ethos for cancer prevention and care at a global level.

After a year of concerted effort, a formal relationship between OERC and INCTR was developed to begin to define the cancer educational needs of low-resource countries. Development of the educational repository proceeded by 1) a establishing cancer taxonomy outline and



Figure 1. Homepage of the OERC site.

Thus, a major challenge will be faced by nations with limited resources. Most evident at present are the deficiencies in human capital and material resources. There is a clear lack of potential for cancer control capacity development at both quantitative and qualitative

2) soliciting, collecting, reviewing, and classifying educational materials, including PowerPoint presentations, course syllabi, monographs, clinical guidelines, videos, research summaries, patient education modules, links to other relevant sites, etc. It was decided that these materials would be made available via the Web Portal hosted by MERLOT (Multimedia Educational Resources for Learning and Online Teaching), (www.merlot.org), the well-established and proven open resource application of the California State University System. Within MERLOT, a new "cancer education community" was established.

The OERC portal, oerc.merlot.org (see figure 1) was announced at the INCTR annual meeting in Antalya, Turkey, and launched online in July 2009. The OERC collection continues to expand, providing no-cost access to materials contributed by the global community of basic scientists and clinical cancer professionals that can be used for self-learning or in the creation of teaching modules relevant to the education and training of healthcare professionals and students, as well as patients, families and the public.

In building the collection of open educational resources, the OERC set goals of not only making materials in the collection available free of cost, but also freely usable. The Creative Commons® policy was selected to serve as the guide to intellectual property rights and explicitly grants users permission to use all or part of the selected materials with appropriate attribution. The OERC collection will be leveraging MERLOT's strategy for providing users assurance of quality and utility. As OERC builds its collection and community of users, we

will establish an editorial board for conducting peer reviews of the collection. MERLOT has an established methodology for peer reviewing materials that it has deployed for the past 10 years. This follows the peer review process of scholarly research (<http://taste.merlot.org/peerreviewprocess.html>). The methodology begins with training the peer reviewers on the three evaluation criteria used in the peer review process:

- 1) quality of the content,
- 2) pedagogical effectiveness, and
- 3) ease of use.

The training provides peer reviewers the guidelines, practices, feedback, and mentoring to develop their skills in conducting valid and reliable peer reviews. MERLOT's peer reviews are published along with other information about the quality and utility of the resource. The provision of analysis and advice by the larger OERC community can help individual users decide if and how the materials can be used effectively in their local context. Furthermore, MERLOT enables individual users to add their advice and experiences about how they were able to use the resource in their local situations and add their observations of outcomes. By using the existing and well-tried methods of MERLOT, OERC enables the community of users, experts and educational content providers to establish additional communication links, adding value to the materials themselves. ■

<http://oerc.merlot.org/>

*Larry Lessin, Diane Kaseman,
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OERC Executive Committee Members*

REPORT ON TELEPATHOLOGY MEETING, ILE-IFE, NIGERIA

Postgraduate Medical Fellowship Training, and by extension, pathology training, began in Nigeria over three decades ago with the establishment of the National Postgraduate Medical College of Nigeria (NPMCN)



Child in clinical facility in OAUTHC in Ile-Ife.

in 1972. Pathology training colleges in Nigeria include the Faculty of Pathology of the NPMCN and the Faculty of Laboratory Medicine of the West African Postgraduate Medical College (WAPMC). The two training colleges have produced more than 300 pathologists in different pathology disciplines. With a population of 140 million people, this number is still very low. As the duration of training lasts on average five years after completion of internship, required for registration, it will take some time to satisfy our needs.

Over 95% of practicing pathologists in Nigeria were trained under these programs, a large majority of whom practice in urban centers.

One approach to solving the problem of the shortage of pathologists is the use of telepathology; a branch

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of telemedicine that involves *the use of telecommunications technology to facilitate the transfer of image-rich pathology data between remote locations for the purposes of diagnosis, education and research* (<http://www.medterms.com/script/main/art.asp?articlekey=33621>).

Telepathology is a low-cost tool for distance diagnosis of pathology cases with the aid of a digital camera-enhanced microscope. It is especially useful in low-resource setting countries, in which practicing pathologists often lack adequate training. In such a situation, materials can be prepared locally, examined, and doubtful cases transmitted by Internet to other pathologists for a second opinion. In some circumstances, photomicrographs prepared by a technician can be sent to a referral center for diagnosis, but in this

case additional training regarding image selection is generally necessary. Telepathology is also a valuable means of exchanging ideas, medical consultation and case discussion even among pathologists in affluent societies.

Telepathology, like telecytology and teleradiology, is fast gaining ground as a versatile medical education tool for both undergraduate and post-graduate medical programs in many parts of the developed world (Lee ES, et al, 2003, Kaplan K, 2004,) and it is also growing in resource-limited societies, where it will turn out to be a very useful diagnostic tool (www.telepatologia.es/9ECT/presentations/Chhut_Vathana.pdf).

The advantages of telepathology are low cost, simplicity and ready and easy accessibility 24 hours a day from any part of the world. Another

advantage is access to any expert, anywhere in the world. Availability of Skype, the free online telephone, is an added advantage if the telepathology system in use does not include audio connectivity.

Static telepathology, (i.e., simply using digital images rather than scanned slides which can be viewed as if on a microscope stage (i.e., moved around and magnified) using computer technology is more commonly used for distributing information globally because of the much smaller file size. It is the system adopted by the University of Pittsburgh (Kaplan K, 2004). One version, known as iPath, was developed and used by the University of Basel, Switzerland (<http://telemet.ipath.ch>), for medical consultation, teaching and continuous education.

This year, the INCTR facilitated the establishment of an iPath telepathology system at the Obafemi Awolowo University Teaching Hospitals Complex (OAUTHC) in Ile-Ife, Nigeria.

The first meeting of the INCTR program on telepathology in Nigeria was held at the Institute of Public Health, Gates Reproductive Health Unit, College of Health Sciences, OAU, Ile-Ife, Nigeria on January 26th, 2010. The program was coordinated by Dr. Nina Hurwitz of the University of Basel Department of Pathology and director of INCTR's Pathology Education Program. The meeting was opened by the Chief Medical Director of the Obafemi Awolowo University Teaching Hospitals Complex OAUTHC, Ile-Ife, Nigeria, Prof. Olusanya Adejuyigbe, followed by an online live goodwill message to participants from the INCTR President, Prof. Ian Magrath, in Brussels.

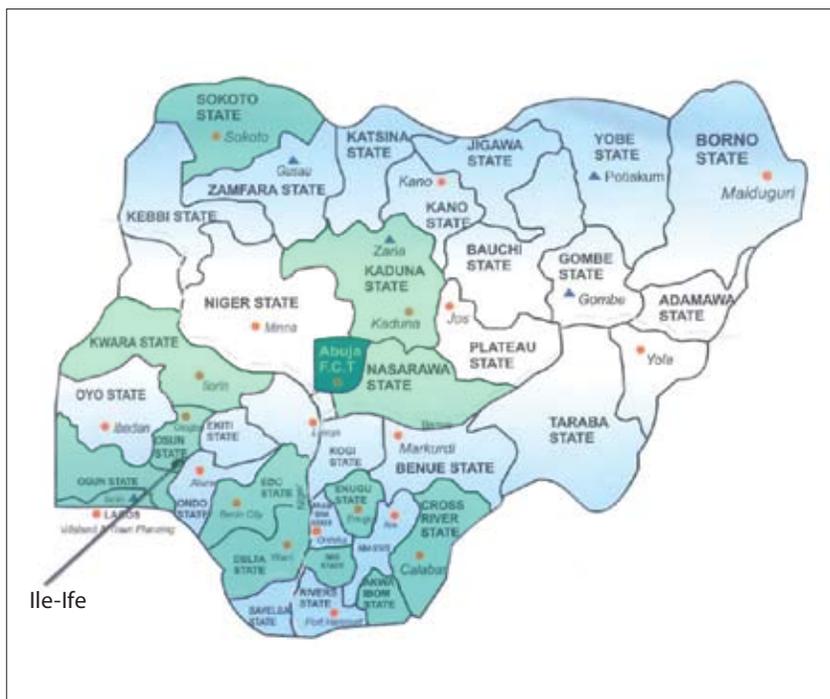


Figure 1. 14 states were represented (darker shading) at the Nigerian Telepathology Meeting in January 2010.

Mr. Philip Bojeghire, the Leica representative in Nigeria, demonstrated the use of the digital camera-enhanced microscope recommended for the program. OAU Internet Service personnel were also available. Other facilitators were Dr. K Adelusola, Ile-Ife; Dr. Rose Anorlu, Lagos and Dr. JB Olasode, of the Morbid Anatomy department, OAUTHC, Ile-Ife, Nigeria.

The meeting was attended by 41 participants from 14 states of the country (figure 1), including pathologists, hematologists and hemat oncologists.

The outcome of the meeting has been very useful, as the host institution acquired the Leica Photomicroscope on the spot, to immediately establish telepathology at OAUTHC, Ile-Ife. Some other participating institutions are making efforts to start the program. The meeting at the Obafemi Awolowo University College of Health Sciences can be regarded as a first step towards the establishment of a national network of telepathology in Nigeria in collaboration with the INCTR. The Director of the Cancer Services in the Federal Ministry of Health, Dr. Patience Osinubi, Abuja and Dr. Dania Simpa, Head Telemedicine Unit, University College Hospital Ibadan, are making great efforts to transform this vision into a reality in the near future. ■

References available at www.inctr.org

Muheez Durosinmi
OAUTHC
Ile-Ife, Nigeria
Nina Hurwitz
INCTR Pathology Program
Sissach, Switzerland

ASSESSMENT VISIT TO NIGERIA AND CAMEROON

Five members of the Pathology Program made assessment visits to several laboratories in Nigeria and Cameroon (see article, this edition) in January 2010. Udo Bode of the pediatric program performed a monitoring visit in Nigeria related to INCTR's ongoing Burkitt lymphoma protocol at the same time. ■

VISIT BY CARY ADAMS, CEO OF UICC

Cary Adams, recently appointed CEO of UICC (now, the Union of International Cancer Control), visited INCTR in Brussels on March 2nd in order to understand better INCTR's work and to begin discussions regarding a closer working relationship. ■

INCTR USA BOARD OF DIRECTORS MEETING

A meeting of the newly constituted Board of Directors of INCTR USA took place on March 30th. ■

A FRANCOPHONE DAY

A day dedicated to cancer control in Francophone African countries was organized in Montpellier on April 7th by Sabine Perrier-Bonnet and attended by the newly appointed President (Pierre Bey) and Vice-President (Martine Raphael) of Alliance Mondiale contre le Cancer (INCTR France). A broad range of topics was covered and much lively discussion took place. ■

LYMPHOMA WORKSHOP, SIENNA

A Workshop on "What we can learn from Africa" organized by Lorenzo Leoncini and members of the Pathology Program was held on May 6-7th in Sienna. The workshop was focused on the diagnosis of hematological neoplasms and included overview lectures and discussions of cases that had, for lack of immunophenotyping, been undiagnosable in Africa. Special tests had since been undertaken in the laboratories of members of INCTR's pathology program. The workshop was extremely successful and much was learned by all participants, mostly from Africa, Europe and the USA. ■

VISIT TO AFRICAN CANCER REGISTRIES

Max Parkin undertook site visits to two African Cancer Registries supported by INCTR in June 2010. ■

For further news see <http://inctr-news.wikidot.com/>

caBIG®: THE NEXT BIG THING

Think of it as a next generation World Wide Web for the medical community — a virtual network of interconnected data, individuals and organizations that has the capacity to redefine how research is conducted, how care is provided, and how patients and participants interact with the biomedical research enterprise.

caBIG®, the cancer Biomedical Informatics Grid, is a biomedical network with the power to capture and analyze huge amounts of biological and clinical data. With the ability to widely disseminate information, caBIG® is a powerful new tool that can bring together medical communities and accelerate research discoveries that are informed by scientists around the world.

The new information technology was first developed at the National Cancer Institute under the leadership of Dr. Kenneth Buetow, whose scientific career has focused for more than 20 years on understanding the role of genetics in complex human diseases such as cancer, and on applying sophisticated informatics technologies to solve major biomedical challenges. At NCI, Dr. Buetow is Chief of the Laboratory of Population Genetics and Director of the Center for Bioinformatics and Information Technology.

"caBIG® resembles the worldwide web in that it is immediate, accessible and highly dynamic," notes Dr. Buetow. "But caBIG® does something beyond those attributes. Because we have 'data about data,' users get the data they want and we can write "smart tools" that

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can find and use data without human intervention and thereby solve 21st century problems.”

Dr. Buetow holds a Ph.D. in human genetics from the University of Pittsburgh. His own research at the Fox Chase Cancer Center in Philadelphia sparked the idea for caBIG®. At Fox Chase from 1986 to 1998, Dr. Buetow’s group generated and electronically distributed the human genetic map.

“It became clear to me that we would exceed the capacity of our current technology, limiting what we could do. It was clear that even large-scale institutions like Fox Chase would struggle with an overload of data being generated, thanks to the vast amount of genomic information becoming available. Part of the reason for my enthusiasm is that I’m not just an IT developer, I’m also a ‘customer’.”

At NCI, Dr. Buetow has spearheaded efforts of the Genetic Annotation Initiative, an attempt to identify variant forms of the cancer genes identified through the NCI Cancer Genome Anatomy Project. He is particularly interested in genetic variations that make individuals more susceptible to liver, lung, prostate, breast and ovarian cancer. His group combines computational tools with bench-top laboratory findings to understand how genes and environment interact to increase cancer risk.

Launched six years ago, caBIG® has been gaining traction. caBIG® is already deployed in more than 56 NCI-designated cancer centers and 16 community cancer centers in the United States. More than 2,000 individuals from 700 institutions have gotten involved. And it’s going global. In addition to a longstanding

partnership in the United Kingdom, the caBIG® community is collaborating with 16 international groups around the world.

The NCI and the UK National Cancer Research Initiative (NCRI) continue to build on a longstanding cooperative effort to support data interoperability. Among these efforts is the



Dr. Kenneth Buetow.

connection of the NCRI’s ONcology Information eXchange (ONIX) portal to caGrid, enabling cancer researchers around the world to access a large number of research databases maintained in the US and the UK. The two are also exploring ways to speed scientific discovery by leveraging the best applications and technologies developed by each organization.

In Latin America, a pilot program is supporting two clinical trials conducted on molecularly characterized stage II and stage III breast cancer patients in Argentina, Brazil, Chile, Mexico and Uruguay. Using caBIG® software tools such as caTissue, caArray, and the caBIG® Clinical Trials Management Suite

(CTMS), researchers can compare data collected at all sites in the study.

In China, Duke University has launched a pilot collaboration with Beijing University Cancer Hospital using caBIG® tools and technology to conduct a Phase II clinical trial for breast cancer. This collaboration marks the first clinical trial in China to conduct all patient registrations electronically. caBIG® is also working with the Shanghai Center for Bioinformatics Technology to develop mutually beneficial exchanges of knowledge and technology.

In Jordan, the NCI is also supporting the development of the new King Hussein Institute for Biotechnology and Cancer near Amman. This center will support basic and translational research while providing state-of-the-art medical care for cancer patients. The collaboration is focused on the adoption of caBIG® tools to provide the standards that will enable data interoperability and the widespread adoption of electronic health records.

Institutions in Australia, Czech Republic, Finland, Germany, the Netherlands, New Zealand and Pakistan are also connected. As more organizations connect to caGrid, notes Dr. Buetow, the value of the data on the network increases.

“The human capital resources in the developing world are truly an untapped resource for solving the world’s problems,” says Dr. Buetow. “Adoption of caBIG® tools and technology allows investigators, the bright minds of the biomedical community, to suddenly have access to state-of-the-art information. Basically, through caBIG® infrastructure, someone anywhere in the world can do the same genomic

analysis, can use the same tools, and can bring equally important insights as anyone working at Broad Institute [the genomic medicine research center affiliated with MIT and Harvard].”

All it takes to delve into a rich and diverse collection of data is access to a computer, an Internet connection and a Web browser.

“There’s a misperception that you need to establish an elaborate infrastructure to benefit from caBIG® technology,” says Dr. Buetow. “With just a username and password, more than 1,000 investigators worldwide are doing analysis on brain cancer data collected in something we call REMBRANDT [the Repository of Molecular Brain Neoplasia Data]. The Cancer Genome Atlas (TCGA) and the Cancer Molecular Analysis portals give users access to data generated from collaborative studies endeavoring to better understand the underlying causes of cancer.”

caBIG® also offers a collection of open source software and infrastructure to enhance the capacity of institutions to manage clinical trials locally. In Pakistan, for instance, one doctor downloaded and installed the software that now supports clinical trials at her hospital.

Researchers are already doing amazing things with caBIG®—retrieving medical images through the National Biomedical Imaging Archive (NBIA) repository, accessing high-quality biospecimens, and combining proteomics, gene expression and other basic research data in a single data management system—but Dr. Buetow is most excited by what the future holds.

“caBIG® is a community-directed activity,” he says. “With open com-

ponents and open work spaces, anyone can join in and determine what direction caBIG® should take. Part of our direction comes from the community itself, people considering how to make the explosion of genomic information useful. Other directions are determined in part by following trends worldwide. For the past year, for instance, we’ve been making sure we can leverage the international investment in health information technology so we can connect research enterprises to delivery centers.”

The caBIG® Annual Meeting in September 2010 drew more than 1,000 individuals—representing 17 countries—to Washington, DC, to consider how the new technology is powering innovative translational research and clinical trials. In its current state, Dr. Buetow noted, the biomedical community is largely a collection of highly fragmented, disconnected silos. IT systems lack the capacity to interoperate. Disparate terms complicate information exchanges between one institution and another. Scientists have to manage “a tsunami” of molecular and clinical data, and islands of information are floating out there, with no standard methodology in place to capture and use that information in scientific studies. caBIG® technology seeks to address each of those challenges.

“caBIG® is about community, connectivity and content,” he remarked during the meeting. “It’s a way of using information technology to bring together disparate and, at times, desperate parts of the biomedical community in general, and the cancer community specifically. Our idea is that by creating

this community, connecting them using information technology, and providing them with rich content, we can transform the face of cancer medicine, and ultimately all of biomedicine.”

It is a breathtaking proposition, but not so far-fetched given the speed of recent technological advances. Dr. Buetow was a graduate student when his lab purchased its first computer. He remembers when the World Wide Web came online. His lab was among the first groups in biomedicine to create a Web site to collect and distribute information.

Within the past ten years, he says, we have experienced a confluence of events that led to the development of caBIG®. High-performance computing, with its large-scale capacity to hold, manage and process data, is now readily available. Internet technology has exploded. And with advances in genome sequencing, a wealth of scientific knowledge at the biological and molecular levels is emerging.

“There’s a critical need for us to take action,” Buetow said at the annual caBIG® meeting. “We need to take advantage of this moment to transform the biomedical system as it stands today. We need to empower this collection of innovators who will take the tsunami of data that is part of the biomedical enterprise and figure out how to convert it from data, to information, to knowledge, and ultimately, to wisdom. We need to figure out how to put this powerful information in the hands of the individuals who can do powerful things with it.” ■

Marcia Landskroener for INCTR

NETWORK

UNIVERSITY COLLEGE HOSPITAL IBADAN, NIGERIA

The University College Hospital, Ibadan (UCH) was established by an Act of Parliament in November 1952 in response to the need for the train-



The 850-bed University College Hospital employs more than 3,600 staff members.

ing of medical personnel and other healthcare professionals in Nigeria and the West African Sub-region. Led by Dr. T.F. Hunt of London, a Visitation Panel in 1951 assessed the clinical facilities for the posting of medical students registered for the M.B.B.S. degree at the University of London. While a Faculty of Medicine had been established in 1948 at the University College, Ibadan (now University of Ibadan), the Visitation Panel rejected the facilities offered by the government-supported Native Authority Hospital at Adeoyo, Ibadan. Accordingly, a new hospital, the University College Hospital (UCH), was planned and building commenced in 1953 at its present site. The new hospital was formally commissioned after its completion in November 1957.

UCH is strategically located in Ibadan, which at the time of the hospital's founding was the largest city in West Africa. Ibadan is also home to Nigeria's first university. With a population of

three million, Ibadan is now the second-most populated city in Nigeria. UCH was initially commissioned with space for 500 beds, but in fact now has a complement of 850 beds.

At its inception in 1948, the hospital had two clinical departments, medical and surgery. Since that time, the hospital has evolved to accommodate about 60 departments, among which is the first Department of Nuclear Medicine in Nigeria, commissioned in April 2006.

The hospital and the University of Ibadan function in excellent symbiosis; it is impossible to think of one without the other in the areas of health workforce training, research and clinical service. This functional interdependence was emphasized from the beginning.

In addition to the undergraduate medical program (based in the College of Medicine of the University of Ibadan), UCH also provides facilities for postgraduate residency training programs in all specialties of internal medicine, surgery, obstetrics & gynecology, pediatrics, otorhinolaryngology, ophthalmology, anesthesia, laboratory medicine, psychiatry, community medicine, general medical practice, radiology, radiotherapy and dentistry. UCH also provides diploma/professional programs in the schools of nursing, midwifery, medical laboratory sciences, and health records and statistics. Tutor courses are offered for environmental health officers, primary health care, community health officers, nurse/midwifery/public health nurse training, and post-registration courses in nursing, e.g., peri-operative nursing and occupational health nursing. UCH also has in-house continuing education programs for nurses and midwives in administration and management,

as well as a plaster room technician training program.

UCH is primarily a tertiary institution but it has undertakes community-based outreach activities at Igbo-Ora, Abedo, Okuku, Sepeteri, Elesu and Jago, where the hospital offers secondary and primary health care.

UCH has 56 services and clinical departments, and runs 96 consultative outpatient clinics a week in 50 specialty and sub-specialty disciplines. In addition to the College of Medicine, the hospital houses a Virus Research Laboratory, a World Health Organization Collaborating Centre in Immunology, and an Institute of Advanced Medical Research and Training. The hospital also houses the Special Treatment Clinic, a state-of-the-art clinic for research, training and the treatment of sexually transmitted diseases, including clinics for people living with HIV/AIDS. UCH recently received accreditation for a new Department of Nuclear Medicine and the Federal Ministry of Health has also granted approval for an Institute of Neurosciences. A pain clinic and a hospice service are also in place for the care of terminally ill patients.

Since its inception, UCH has trained 6,051 doctors, 501 dentists, 4,513 nurses, 2,307 midwives, 471 peri-operative nurses, 1,062 laboratory scientists, 576 tutors for environmental health officers, 451 nurse/midwife/public health educators, 326 primary health information management personnel (formerly referred to as medical records officers) and 1,394 resident doctors.

Patient visits in the Accident and Emergency (A&E) Department of the hospital average 6,000 annually, and about 150,000 new cases are seen in the various clinics every year. In 2001, UCH reached the million-patient mark. Due

PARTNER PROFILE

to the aforementioned facilities, manpower and track record, UCH enjoys wide patronage and both national and international collaboration.

UCH, Ibadan has a governance and management structure that essentially consists of a series of departments for each major clinical field. Its Chief Medical Director, assisted by the Chairman of the Medical Advisory Committee is responsible to the Board of Management which, in turn, falls under the Federal Ministry of Health. Administrative decisions are taken by the Director of Administration.

NUCLEAR MEDICINE DEPARTMENT

The newly established nuclear medicine department, the first ever in Nigeria, has commenced bone-scanning services using radio-pharmaceuticals. This service is available both for medical and oncological diagnosis and treatment. Diagnostic medical endoscopies of both upper and lower gastrointestinal tracts have been performed at the UCH since the 1980s. The newly refurbished endoscopy unit has broadened the range of services that now includes fibro-optic endoscopy of the esophagus.

VISION

Our vision is to be the flagship tertiary health care institution in the West Africa Sub-region, offering world-class training, research and services; we aim to be the first choice for patients seeking health care in a safe environment known for a culture of continuous quality care.

UCH MISSION

The UCH mission is to render excellent, prompt, affordable and accessible care in an environment that promotes hope and dignity, irre-

spective of status, whilst developing high-quality health personnel in an environment that stimulates excellent and relevant research.

CORE VALUES

The core values of UCH are:

- Unrestricted access to excellent training, research and services
- Prompt, accessible, affordable and compassionate patient-centered care
- Professionalism and teamwork
- Equity in service provision
- Transparency and accountability
- Prudence in resource management
- High quality staff capacity and a competitive reward system
- Promoting collaboration with stakeholders

RESEARCH

Research has always been important to the UCH mission. The hospital provides short-term continuing training

Nursing services

Assistant Directors of Nursing	74
Chief Nursing Officers	141
Principal Nursing Officers	101
Senior Nursing officers	212
Nursing Officers	143
Staff Nurses	371
Senior Staff	784
Junior Staff	1010

Medical Trainees

Residents	320
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Medical Consultants

Laboratory Physicians	
- Histopatologists	7
- Hematologists	6
- Medical Micropathologists	6
- Chemical Pathologists	6
Surgeons	35
Family Physicians	11
Pediatricians	17
Obstetrics & Gynecologists	21
Radiologists	9
Radiotherapists	6
Internal medicine Physicians	21
Dental Surgeons	23
Anesthesiologists	15



Professor Aken'Ova with consultant hematologists and residents.

as well as continuing education of its staff to achieve effective and efficient delivery of healthcare services.

Ten most common cancers seen at the University College Hospital between 2000 and 2009 were:

Male	Female
Prostate	Breast
Lymphoma	Cervix uteri
Colo-rectal	Ovary
Liver	Lymphoma
Bone marrow	Colon & rectum
Nasopharynx	Endometrium
Larynx	Bone marrow
Urinary bladder	Thyroid gland
Brain	Liver
Stomach	Brain

Most common childhood tumors at UCH Ibadan:

- Retinoblastoma
- Burkitt's Lymphoma
- Malignant Lymphoma
- Nephroblastoma
- Rhabdomyosarcoma
- Leukemia
- Osteosarcoma
- Brain Tumors
- Neuroblastoma
- Fibrosarcoma

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NETWORK

PROFILE IN CANCER MEDICINE

METRONOMICS: A SILENT REVOLUTION

According to the head of the Department of Medical & Pediatric Oncology at Tata Memorial Hospital, the most important challenge in cancer medicine in India is not finding a cure but developing effective and affordable therapies. Since accepting the helm of the medical oncology department in India's largest and most advanced cancer hospital, Dr. Shripad Banavali has embraced a revolutionary approach to cancer treatment known as metronomic therapy. With this approach, well-proven chemotherapeutic agents are administered to patients at low doses at regular intervals over an extended period of time. The debilitating side effects of high-dose treatments are minimized and the treatment can be administered in smaller cancer centers with minimal supportive care.

"I have always strived to develop innovative, simple, affordable treatment protocols," Dr. Banavali says, noting the oral protocol for acute myeloid leukemia he has been using for pediatric patients on an outpatient basis with excellent results. A similar treatment protocol is now being implemented for other leukemias and non-Hodgkin's lymphoma, as well as for cancers of the head and neck, ovary, breast and gastrointestinal tract.

Under his direction since 1998, Tata's pediatric leukemia/lymphoma clinic has significantly improved five-year outcomes by modifying existing protocols or adapting new protocols. Five-year event-free survival rates improved from 62% to 86% for T-ALL; from 57% to 76% for non-T-ALL; from 57% to 81% for ALL in children between the ages of 1 and 3; from 42% to 96% in T-lymphoblastic lymphoma, and from 62% to 93% in diffuse large B-cell lymphoma. In acute promyelocytic leukemia, overall survival rates



Dr. Shripad Banavali.

drastically improved from 25% to 79%.

Dr. Banavali earned a degree in internal medicine at University of Bombay, and completed adult oncology training at Tata Memorial Hospital under the guidance of Dr. SH Advani. During this time he wrote a research project on chronic myeloid leukemia for which he earned a fellowship to work with Dr. Harvey Priesler at the University of Cincinnati Medical Center. He spent nearly three years there, conducting research on various aspects of leukemia and especially the CD 34+ hematogenic progenitor cells.

In 1992, he moved to Memphis, Tennessee, to work at St. Jude Children's Research Hospital. There he completed his board certification in pediatrics and a clinical fellowship in pediatric hematology-oncology. Within the Department of Experimental Oncology, he worked on a project involving the development and utilization of an in-situ FISH technique to isolate the gene involved in the pathogenesis of neuroblastoma.

"The fellowship at St. Jude was immensely helpful to me. The high level of research and training made me a better-rounded oncologist. But I always knew I would return to India," Dr. Banavali

says. "I wanted to work where I could do the most good."

Dr. Banavali has been working with INCTR since its inception, particularly in the formulation and execution of various INCTR protocols in leukemias, lymphomas and retinoblastoma. He has also been involved in efforts to develop guidelines for the management of pediatric cancers in low-resource countries.

At St. Jude, he says, the doctor/patient ratio is very high. At Tata Memorial Hospital, doctors see nearly 44,000 new cancer patients every year — 2,000 of whom are under the age of 18 and cared for by only six pediatric oncologists (in the USA, a reasonable ratio would be 3-4 pediatric oncologists for every 50 patients, and most centers would see only 50-100 patients per year!).

As a government-funded cancer institute, Tata Memorial Hospital treats up to 60% of its patients at no cost. The hospital's goal is to provide a high level of patient care while also supporting research and clinical training in all fields of cancer medicine.

Even with the workload at TMH, Dr. Banavali regularly visits BKL Walawalkar Hospital, and has helped it to develop as a Rural Comprehensive Cancer Center.

As the demand for low-cost cancer treatment grows, so does interest in metronomic therapy, an approach that uses traditional chemotherapies developed in the 1950s, '60s and '70s. "Given orally, these therapies are simple to administer, they're inexpensive — as little as \$4 a month, and they don't require a lot of infrastructure," notes Dr. Banavali. "This has significant implications for the care of patients in developing countries and elsewhere. The cost of cancer treatment is becoming an important factor, even in the West." ■

Marcia Landskroener for INCTR