
INCTR

Mission, organization and achievements

The International Network for Cancer Treatment and Research (INCTR) is an international nongovernmental organization (NGO) that was established to address a neglected global health problem – the ever increasing burden of cancer in developing countries. The founder members of INCTR included the former Institut Pasteur in Brussels and the International Union Against Cancer, now known as the Union for International Cancer Control (UICC). The National Cancer Institute in the United States provided financial and technical support and the organization began its activities in 2000. INCTR's headquarters are located in Brussels and it has offices and branches throughout the world. INCTR became an NGO in Official Relations with the World Health Organization (WHO) in January 2010.

The need for INCTR: Cancer in developing countries

Approximately 85% of the world's people live in low- or middle-income countries (LMICs). In 2012, Globocan estimated that there were approximately 14.1 million new cases of cancer and 8.2 million deaths from cancer in the world, with 65% of deaths occurring in LMIC. The number of cancer cases continues to rise across the world, but much faster in LMICs because development brings decreased mortality and with their higher fertility rates, this rapidly translates into population growth and increased numbers of patients with common diseases. The birth rate subsequently declines, although population growth continues since people live longer. Eventually birth and death rates stabilize at a much lower level of both than was the case prior to development. These demographic changes are accompanied by the adoption of unhealthy lifestyles practiced in high-income countries, particularly smoking, and increasingly, overeating and a sedentary lifestyle.

Resources of all kinds for treating cancer are limited in LMICs, such that patients who develop cancer frequently lack access to a facility capable of making an accurate diagnosis and providing appropriate therapy. There is a lack of drugs, a paucity of radiation therapy facilities and very few cancer specialists or other health care workers who are needed to effectively care for cancer patients. Diagnosis may be so delayed that there is little that can be done even if the patient does finally reach a facility competent to care for them. Terminal care is not widely available, and regulations and attitudes are still largely directed towards preventing the misuse of opioids rather than relieving the pain of

dying patients, such that most patients die without symptomatic relief or little or no mental or spiritual comfort. It is estimated, for example, that less than 1% of patients who need palliative care in India receive it.

INCTR is unique in that it focuses only on the developing world. It also works directly with its collaborators, sometimes visiting them many times in order to achieve its goal of helping to build sustainable capacity in LMICs in order to assist these countries in cancer prevention, early diagnosis, treatment and palliative care. It is not an advocacy organization, and all clinical projects are coordinated by a health professional. Its output is information collected in the field, lives saved by cancer prevention or treatment, and improved quality of palliative care.

Who INCTR works with

INCTR utilizes healthcare professionals familiar with the problems of developing countries to enable it to achieve its goals. See Box 1.

INCTR'S GOALS – MAKING A DIFFERENCE

- ➔ To reduce the incidence of cancer in resource-limited countries through public and professional education about the causes of cancer and how to use this information in cancer prevention
- ➔ To detect cancer early through public and professional education about the early signs of cancer and what to do if they appear
- ➔ To diagnose cancer accurately through pathology training and, where important and feasible, imaging techniques

INCTR develops local capacity within LMICs by training healthcare professionals to establish “centres of excellence” in the delivery of feasible, affordable and effective care, including palliative care, that is considered “best practice” so that they, in turn, can train others within their country or region.

INCTR works through its branches in implementing various programmes and projects conducted in collaboration with partner institutions in developing countries and monitored by field visits.

INCTR integrates research into its programmes by documenting and evaluating actual data (rather than projected economic or health benefits, for example). Such research may include a wide range of projects, from cancer education for the general public to developing treatment outcomes, including palliative care. This, in turn, enables healthcare professionals working in LMICs

Figure 1: Disease burden and resources

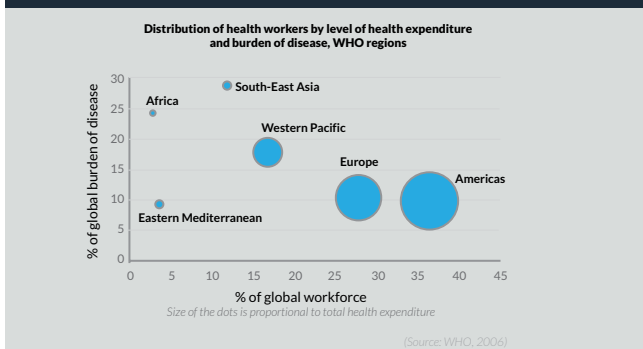
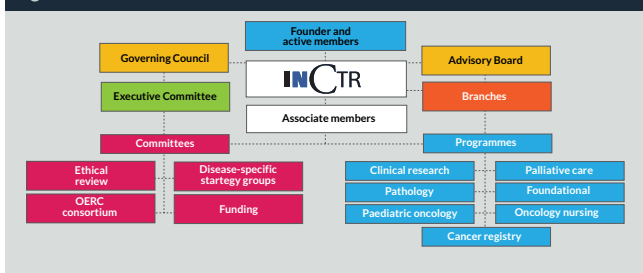


Figure 2: Disease burden and resources



to become familiar with the most pressing issues and to develop plans to improve efficiency and reduce cost. Although clearly many countries have limited health workforces and quantitation of such workforces can be valuable in terms of planning for the future, it realizes that many cancer plans have little impact because of the limited resources and great difficulty in expanding interventions to very poor populations which cannot “purchase” their own healthcare needs and which have little or no chance of expanding their present resources. Having a cancer plan is not enough. Successful cancer plans require knowledge and a budget in addition to educated health professionals.

INCTR's structure

INCTR has consultants and volunteers dedicated to the accomplishment of its goals. Although its headquarters are located in Brussels, it has branches in the United States, Canada, Brazil, United Kingdom, France, Egypt, Nepal and India. Branches are legally-established NGOs that contribute to and conduct programmes and projects that are relevant to INCTR's mission.

Resource development, administration and programmes (e.g., adult oncology, paediatric oncology, cancer registries, pathology and palliative care) are supervised by an Executive Committee or directly by the branches. The Executive Committee is responsible to INCTR's Governing Council. Programmes and projects are developed with the participation, input and advice of various INCTR committees and strategy groups, as well as independent scientific advisers. Programmes and projects are conducted in collaboration with partner institutions involved with cancer research, diagnosis and treatment, including palliative care and education in countries with limited resources.

STRATEGIES

- ➔ To build capacity for cancer prevention, diagnosis, treatment and palliation through professional education and training
- ➔ To conduct, or provide materials for the conduct of educational campaigns for the public and primary care doctors about the causes of cancer and living a healthier life
- ➔ To work with experts in-country to conduct locally relevant research on cancer control

Individuals, institutions or organizations often choose to serve as Associate Members who contribute financially to the work of INCTR.

What does INCTR do?

INCTR addresses all aspects of cancer control with the overall goal of lessening the morbidity and mortality from cancer. It emphasizes training and education of healthcare professionals in LMICs to ensure that “best practices” are instilled in cancer prevention, early diagnosis, treatment and palliative care. Research is an integral part of its work with its partners in LMICs in order to accurately document the cancer burden – including the types of cancer and extent of disease, the outcomes of prevention and early detection campaigns and the efficacy, toxicity and cost of treatment delivered. It also emphasizes public awareness of cancer, which is an essential component of early diagnosis. INCTR has a variety of programmes that are carried out in close collaboration with its branches as well as its partner institutions in developing countries. INCTR's current programmes include:

- ➔ adult oncology;
- ➔ clinical research;
- ➔ palliative care;
- ➔ pathology;
- ➔ cancer registry;
- ➔ foundational;
- ➔ paediatric oncology;

INCTR's projects and achievements

Each INCTR programme has goals and objectives in line with the overall mission of the organization, divided into separate projects. Many projects have been conducted or are on-going and include:

Adult oncology

- ➔ Prevention, early diagnosis, and treatment of selected cancers in poor urban areas and in rural and tribal regions in the state of Rajasthan in India.
- ➔ Cervical cancer screening using visual inspection in Nepal and Tanzania.
- ➔ Training of Bolivian healthcare professionals in cervical cancer screening by Peruvian experts.
- ➔ HPV vaccination of young girls in Nepal.

Cancer registries

- ➔ Establishing an East African Registry Network (EARN) that subsequently became the African Cancer Registry Network

(AFCRN). As part of the Global Initiative for Cancer Registry Development in LMICs, the Network acts as a consortium to provide a “regional hub” for cancer registries in sub-Saharan Africa. The AFCRN is supporting or assisting the development of 22 cancer registries in the region, including English- and French-speaking countries.

- ➔ Provision of training courses in cancer registration and the use of CanReg 5.
- ➔ Participation in collaborative international research.
- ➔ Visits of INCTR consultants to the Kingdom of Saudi Arabia to review cancer registration procedures and data quality and to Uganda to offer advice on setting up a cancer registry.

Clinical research

- ➔ The treatment and characterization of acute Lymphoblastic Leukemia in children, adolescents and young adults in India – over 450 patients have been treated by four institutions.
- ➔ The treatment and characterization of Burkitt Lymphoma – over 750 patients have been treated by seven centres in Nigeria, Democratic Republic of Congo, Uganda, Kenya and Tanzania. Survival is greater than 60% at 5 years.
- ➔ Understanding problems faced by parents of children with Retinoblastoma before treatment – 435 parents interviewed from institutions in 10 countries in Latin America, Asia and Africa.
- ➔ Situational analysis of breast cancer – 8,800 medical records of women treated for breast cancer in four institutions in Peru, Egypt, Pakistan and India.
- ➔ Studies carried out in Brazil, India, Pakistan and Turkey to determine delays in diagnosing and treating nasopharyngeal carcinoma and assess the role of consanguinity and familial history in this cancer.
- ➔ A new initiative to characterize the lymphoproliferative diseases in adults in Senegal with initiated in partnership with Universities in Dakar.
- ➔ Development of a pathological and radiological review for Brazilian patients with medulloblastoma in partnership with the Brazilian Society of Paediatric Oncology.

Foundational

- ➔ Accreditation Programme in the conduct of clinical trials in institutions in Brazil.
- ➔ Educating school children about cancer in Nepal.
- ➔ Evidence-based development through preparation of bibliographies of published literature from developing countries relevant to breast cancer and selected cancers in Egypt.
- ➔ Open Educational Resources for Cancer available online.
- ➔ Thematic workshops to discuss challenges in cancer control

in East Africa.

- ➔ Webinars for e-learning.
- ➔ Publication of five annual editions of *Cancer Control* from 2013, with specialist healthcare publisher, Global Health Dynamics, looking at all aspects of cancer policy, prevention, detection, treatment and palliation.

Palliative care

- ➔ Training and educating healthcare professionals – doctors, nurses and social workers in the principles of palliative care – in Brazil, Cameroon, Burkina Faso, Sénégal, Mali, Tanzania, India and Nepal.
- ➔ Sensitization workshops for government officials and the public in Brazil, Tanzania, India and Nepal.
- ➔ Development of a centre of excellence in palliative care for both adults and children in Hyderabad, India.
- ➔ Lobbying governments to improve access to opioids for terminally-ill cancer patients – Nepal and India.
- ➔ Establishment of twinning programmes with hospices in Canada that support palliative care efforts in Nepal.
- ➔ Fostering the establishment of palliative care societies – in Nepal and Pakistan.
- ➔ Promoting paediatric palliative care in Pakistan.
- ➔ Publishing a palliative care handbook describing the management of a wide variety of symptoms in English, Portuguese, French and Turkish.
- ➔ Development of the “Life at Your Doorstep” home care programme offering extensive, 24/7 support for patients and families struggling with advanced and terminal illness in the cities of Hyderabad and Secunderabad.
- ➔ Organized training course for Francophone sub-Saharan Africa in Uganda. This was led by HASPF and the Institute of Hospice and Palliative care in Africa with expert input by Hospice Africa Uganda and Alliance Mondiale Contre le Cancer.
- ➔ Palliative care workshops and training courses for Francophone sub-Saharan Africa organized by AMCC in partnership with AFSSO were held in Uganda and Ivory Coast.
- ➔ Establishment of palliative care centres of reference and training in sub-Saharan Francophone Africa (Mali, Cameroon, Ivory Coast).
- ➔ Canadian branch provides training in India for St Mary Hospital in palliative care and fosters a collaborative approach between palliative care and health care in Nepal.
- ➔ Development of palliative care programme in Rajasthan, India.

Paediatric oncology

- ➔ Establishment of centres of reference for the treatment of

development of a common treatment protocol for Wilms Tumour.

- ➔ Conducting workshops and symposia on topics of relevance in developing countries.
- ➔ Promotion of the establishment of paediatric oncology societies – Philippines and Pakistan.
- ➔ Development of a centre of excellence in paediatric oncology at the Santa Marcelina Hospital/TUCCA in São Paulo, Brazil.
- ➔ Conducting a campaign for the early diagnosis of retinoblastoma including, but not limited to, the translation of a film showing a child with early retinoblastoma into 12 languages and distributing the film around the world (Brazil); development and wide dissemination and display of posters (Mexico and Brazil); and establishment of a retinoblastoma day (Turkey and Brazil).
- ➔ Ophthalmology nurses from the Democratic Republic of Congo trained in France to fit prosthetic eyes following enucleation (surgical removal of the eye) for the treatment of retinoblastoma.

Pathology

- ➔ Central pathology review of Burkitt Lymphoma in institutions participating in the treatment protocol for this disease in Africa.
- ➔ Training and education workshops for pathologists and clinicians.
- ➔ Training and education workshops for technicians and pathologists in techniques to improve diagnostic capabilities.
- ➔ Use of iPath – an internet telepathology programme – for consultation, training and education.
- ➔ Provision of training and education of haematopathologists in Francophone African countries (Cameroon, Democratic Republic of Congo, Sénégal).
- ➔ “What can we learn from Africa” pathology workshop held in Arusha, Tanzania for pathologists from Senegal, Benin and Democratic Republic of Congo to improve the ability of African haemato-pathologists to diagnose haematopathological neoplasms using the World Health Organization Classification.
- ➔ Setting up of a project to characterize lymphoproliferative disorders in adults in Senegal in partnership with local universities.
- ➔ Programme to improve pathologic and haematologic diagnostics established in Ethiopia using onsite and online training, education, and consultations.

Psychosocial support

- ➔ Development of an educational programme relating to the psychosocial needs of cancer patients in conjunction with the

Brazilian Society of Paediatric Oncology.

World Health Organization

- ➔ Organized the 2009 update of the WHO Essential Medicines List for Cancer.
- ➔ Participated in guideline updating and development (cervical cancer, Kaposi sarcoma and referral guidelines for breast and cervical cancer).
- ➔ Consultation with Dr Jean Marie Dangou, Head of AFRO (African Regional Office of WHO) on non-AIDS defining malignancies in HIV positive individuals.
- ➔ INCTR organized an advisory meeting for WHO AFRO relating to the issue of AIDS-related but non-AIDS defining cancers in Africa. A report was provided to AFRO.
- ➔ Advising EMRO on a planned high-level meeting in the region late in 2014.
- ➔ INCTR is participating in the development of recommendations for the management of cancer in the Eastern Mediterranean region. INCTR’s particular focus will be cancer information and the development of a tool that countries can use to identify their strengths and weaknesses with respect to cancer control, and develop or modify plans accordingly.

Considerable attention will be paid to the identification of methods of collecting and assessing the quality of data, the use of data in making scientific observations and/or the creation of evidence essential to establishing effective treatment programmes. INCTR will work more closely with governments in this regard, and funding for training, projects, scientific studies etc. will come from both within the country and outside the country. Every attempt will be made to ensure that programmes are self-sustaining after a reasonable time has passed.