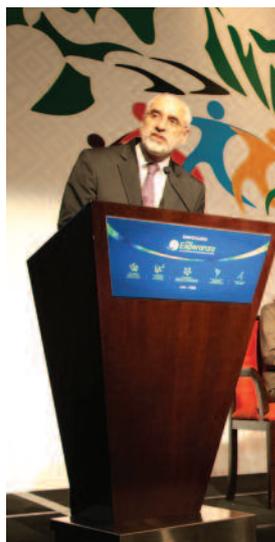


# CANCER CONTROL 2014

## SUPPLEMENT 1: ICCC-5



**THE FIFTH INTERNATIONAL CANCER CONTROL CONGRESS**  
3-6 NOVEMBER 2013, LIMA, PERU



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PRECISION PRINTING, UK

**THE CANCER CONTROL 2014 SUPPLEMENT 1: ICC-5**  
IS PUBLISHED BY GLOBAL HEALTH DYNAMICS LIMITED  
FOR THE INTERNATIONAL CANCER CONTROL CONGRESS  
ASSOCIATION

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ISBN 978-0-9576072-2-4

FIRST PUBLISHED 2014



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# THE FIFTH INTERNATIONAL CANCER CONTROL CONGRESS

**SIMON B SUTCLIFFE**, INTERNATIONAL CANCER CONTROL CONGRESS ASSOCIATION (ICCCA), VANCOUVER, CANADA AND **TATIANA VIDAURRE ROJAS**, INSTITUTO NACIONAL DE ENTERMEDADES NEOPLASICAS (INEN), PERU

Over the past decade, the International Cancer Control Congresses (ICCCs) have striven to promote population-based cancer control. In 2005, when the first ICCC was held in Vancouver, Canada, the goal was to raise awareness about the need for population-based, national cancer control plans. As these have become more established, ICCC has further evolved to address: cancer and noncommunicable disease plans; the need to move beyond planning to implementation; the requirement for integrated activity across public/population health and clinical medicine; the recognition of differing “contexts” for cancer/noncommunicable disease (NCD) control in differing cultural and regional settings; and the necessity for collaboration across disciplines and sectors of practice and between agencies, institutions and nations as a means of learning, teaching and sharing how best to advance population disease control. For each ICCC, the goal has been to impact the cancer and NCD control plans and practices of the host organization and regional and international partners through catalyzing participant interaction within a global forum.

For ICCC-5, a “logic model” was developed to align the purpose, goals, directions, inputs and outputs of the Congress. Key outputs included the creation of a neutral forum to facilitate discussion of ideas and exchange of information regarding sustainable regional cancer and integrated NCD plans; linking the global cancer and NCD agendas and exchanging ideas about how global commitments are being realized at national and regional levels; addressing regional, political and policy level key targets identified in the UN Global Action Plan (1); continuing development of regional broad-based action plans for integrated cancer and NCD control plans; increasing momentum to share progress towards targets through 2014–2025; fostering partnerships and collaborations between countries and international agencies to maximize expertise and resources; and providing the opportunity to share, exchange and develop

capability for cancer and NCD control within the host country (Peru), the region (RINC, Latin America) and at a global level.

Implementation of cancer and NCD control plans requires alignment of resolve and support – both “top-down” (political and professional) and “bottom-up” (advocates, patients and public). Without this alignment of purpose, population-based disease control plans are merely “medical documents”, rather than “blueprints” for societal change and health advance. To promote alignment and dialogue, stakeholders from all disciplines and sectors involved in cancer/NCD control were invited and encouraged to attend. The co-hosts of the Congress were the International Cancer Control Congress Association (ICCCA), National Cancer Institute of Peru (INEN) and the Ministry of Health, Peru (MINSa). The World Health Organization (WHO) was the co-sponsor. The meeting was endorsed and supported by the President and First Lady of Peru, the government and Ministry of Health of Peru, the government of Canada (PHAC and CPAC), RINC (the Association of National Cancer Institutes in Latin America and the Caribbean), ISNO (International Society of Nurses in Oncology), the Pan American Health Organization (PAHO/WHO), several international cancer agencies (IAEA-PACT, NCI/US, ACS/US, INCTR, UICC, IARC) and patient advocacy organizations (Esperanza, Peru and Campaign to Control Cancer, Canada). Through full engagement and active participation of patients, public health professionals, including administrators, and politicians (policy-makers) ICCC-5 aspired to move conventional medical thinking about cancer and NCDs to a new level – the control of cancer as an “all of society” commitment.

## The ICCC-5 Programme

ICCC-5 in Lima, Peru, examined key themes in cancer/NCD control in five sessions:

- Improving and sustaining prevention in cancer.
- Mobilizing “all of society” for effective cancer control.



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# THE FIFTH INTERNATIONAL CANCER CONTROL CONGRESS

## SESSION 1: IMPROVING AND SUSTAINING PREVENTION IN CANCER CONTROL

# SESSION 1: IMPROVING AND SUSTAINING PREVENTION IN CANCER CONTROL

**GRAHAM A COLDITZ**, INSTITUTE FOR PUBLIC HEALTH, AND SITEMAN CANCER CENTER, WASHINGTON UNIVERSITY IN ST LOUIS, USA; **EDUARDO CAZAP**, LATIN AMERICAN AND CARIBBEAN SOCIETY OF MEDICAL ONCOLOGY (SLACOM), BUENOS AIRES, ARGENTINA/UNION FOR INTERNATIONAL CANCER CONTROL (UICC), GENEVA, SWITZERLAND/NATIONAL CANCER INSTITUTE (INC), BUENOS AIRES, ARGENTINA; **JAVIER MANRIQUE-HINOJOSA**, INSTITUTO NACIONAL DE ENFERMEDADES NEOPLÁSICAS (INEN), LIMA, PERU; **NEAL PALAFOX**, DEPARTMENT OF FAMILY MEDICINE AND COMMUNITY HEALTH AND PACIFIC CANCER PROGRAMS, JOHN A BURNS SCHOOL OF MEDICINE, UNIVERSITY OF HAWAII, HONOLULU, USA; **GUSTAVO SARRIA BARDALES**, DEPARTAMENTO DE RADIOTERAPIA, INSTITUTO NACIONAL DE ENFERMEDADES NEOPLÁSICAS (INEN), LIMA, PERÚ; **ANDREAS ULLRICH**, WORLD HEALTH ORGANIZATION (WHO), GENEVA, SWITZERLAND; **ROXANA REGALADO**, NORMATIVIDAD, CALIDAD Y CONTROL, NACIONAL DE SERVICIOS ONCOLÓGICOS, INSTITUTO NACIONAL DE ENFERMEDADES NEOPLÁSICAS (INEN), LIMA, PERU; **FRANCISCO TEJADA**, DEPARTMENT OF EPIDEMIOLOGY AND PUBLIC HEALTH, UNIVERSITY OF MIAMI, MIAMI, USA; **MILTON SORIA HUMEREZ**, INSTITUTO NACIONAL DE LABORATORIOS EN SALUD, BOLIVIA; **CATHERINE G SUTCLIFFE**, DEPARTMENT OF EPIDEMIOLOGY, JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH, BALTIMORE, USA; **SIMON B SUTCLIFFE**, INTERNATIONAL CANCER CONTROL CONGRESS ASSOCIATION (ICCCA), VANCOUVER, CANADA AND **THE ICC-5 WORKING GROUP**

The rising global burden of noncommunicable diseases (NCDs), including cancer, has reoriented strategy from single disease plans to integrated strategies to control diseases sharing common causal risk factors. This evolving process encompasses the urgent need to move beyond planning to implementation; the requirement for integrated activity across public, population health and clinical medicine; the recognition of differing settings for cancer and NCD control in differing cultural and regional scenarios; and the need for collaboration across disciplines and sectors of practice and between agencies, institutions and nations as a means of learning, teaching and sharing how best to advance population disease control.

Session 1 of the Fifth International Cancer Control Congress (ICCC-5) focused on how individual and societal factors influence cancer and NCD risk, through two plenary presentations, a panel discussion and four interactive workshops: (1) individual and provider-level interventions to reduce cancer risk; (2) community-based interventions to reduce cancer risk; (3) policy-based interventions to reduce cancer risk; and (4) regional interventions to reduce the risk of cancer. Workshop discussions highlighted the importance of awareness and communication with health care providers. Many preventive services begin with primary care providers and their engagement and endorsement can reinforce broader prevention programmes delivered in the community. Beyond providers, involvement of all interested stakeholders in cancer prevention is necessary to reach all members of the society. When delivering prevention messages, tailoring these messages to the community is an important component for engaging society in prevention. To increase the efficiency of prevention programmes, evaluations that quantify aspects of the process, performance, and impact of prevention messages and interventions are required. For cancer prevention strategies to be successful, convening and making recommendations is necessary but insufficient. Implementation of actions, ensuring that capacity for response is appropriate and measuring and reporting interventional programme development and delivery is essential for effective response.

*Key words: cancer prevention, global health, cancer control, Latin America*

## Introduction

*Graham A Colditz, Washington University in St Louis, USA and Eduardo Cazap, SLACOM*

Population-based cancer control and the need for national cancer control plans has become generally accepted (1, 2), and more recently, this concept has evolved to the more comprehensive and combined strategy of cancer and noncommunicable diseases (NCDs) (2). The clear demonstration of this evolution has been the unanimous approval of the Political Document at the United Nations High Level Meeting on NCDs in September 2011 (3, 4).

The world is facing a new stage of this evolving process: the urgent need to move beyond planning to implementation; the requirement for integrated activity across public, population health and clinical medicine and the recognition of differing settings for cancer and NCD control in differing cultural and regional scenarios (5). There is also a necessity for collaboration across disciplines and sectors of practice and between agencies, institutions and nations as a means of learning, teaching and sharing how best to advance population disease control (6).

The purpose of this session entitled “Improving and sustaining prevention in cancer control” was to discuss the individual and societal factors that influence cancer and NCD risk (5, 7). The discussion was placed in the context of their relative contribution to the burden of disease and the time frame for prevention benefits (8). The questions discussed were:

- ▶ What are the individual and societal factors that influence cancer and NCD risk?
- ▶ How can we intervene?
- ▶ What are the barriers to implementing interventions?
- ▶ What lessons can we learn from both successful and failed strategies?

## Methodology and objectives

ICCC-5 Session 1 on “Improving and sustaining prevention in cancer control” comprised two plenary presentations and a panel discussion to provide an overview of the subject matter as a means of preparing Congress participants for participating in four, small group, interactive workshops on relevant topics to be addressed in greater depth. Selected abstracts providing particular insights into the topic area were presented orally by the authors in each of the workshops. Workshop leaders were encouraged to conclude their workshops with a brief set of prioritized recommendations to identify the key directions for further development of interventional activities beyond this Congress.

The objective of this session was to explore the individual and societal factors that influence cancer and NCD risk. The following four issues were selected for in-depth discussion in the workshops:

- ▶ Individual and provider-level interventions for reducing cancer risk.
- ▶ Community-based interventions for reducing cancer risk.
- ▶ Policy-based interventions for reducing cancer risk.
- ▶ Regional interventions for reducing cancer risk.

## Plenary presentations

### 1. Cancer and NCD prevention from a global perspective

*Graham A Colditz, Washington University in St Louis, USA*

The burden of cancer is predominantly experienced in low- and middle-income countries (9). Changing patterns of fertility and economic development add to the rising age-specific incidence of cancer with rapid increases in breast cancer in many countries. In fact, breast cancer accounts for 25% of all cancer diagnoses worldwide among women in 2012 (9). To address the global burden of cancer, we must overcome scepticism that cancer can be prevented. Successful prevention interventions require the broader community and population health perspectives, and must sustain individual behaviour changes in the context of the health care system and broader societal influences on behaviour and health.

While more than 50% of cancer is preventable (8), the burden due to infectious causes is greater in low- and middle-income countries (10). Obesity, lack of physical activity, poor diet and smoking cigarettes remain the dominant causes of cancer and other chronic diseases including diabetes and heart disease. Prevention must operate across many sectors to achieve population health benefits as is evident for obesity (11,12). WHO priorities for population-wide interventions offer the best approaches to sustain improvements in health (5). These include: reducing tobacco use (a WHO best buy (13)); promoting physical activity; reducing harmful alcohol use; promoting healthy diets; and specific cancer-focused strategies that include Hepatitis B vaccine (a best buy); HPV vaccine; and cervical cancer screening.

### 2. Esperanza: The population cancer control plan in Peru

*Jose Del Carmen, Vice Minister of Health, Ministry of Health, Peru*

The impact of cancer on the expectations and quality of life of

the population can be addressed at multiple levels, including public policy, the environment, communities, health care organizations, professional teams, families and individuals. Strategically, intervening at the interfaces between the different levels has the potential to produce greater effects on population health than working on one level.

Each year an estimated 45,000 new cases of cancer occur in Peru and 75% of them present at an advanced stage. To address this and other challenges, the country is promoting a process of health reform, aimed at achieving universal coverage protection and health care for the entire population. Progress on the framework of “universal insurance” began in 2009 and has successfully extended health protection coverage to an estimated 12 million Peruvians living in poverty whose health care is funded with state resources and provided in public hospitals. In addition, the “List of diseases at high cost”, which includes treatment for cancer of the cervix, breast, colon, stomach, prostate, leukaemias and lymphomas (plus CKD), was approved in 2012, thereby optimizing funding from Public Security (SIS) for cancer treatment through extraordinary coverage procedures or special cases.

This development, however, produced limited results due to the lack of adequately equipped and staffed services across the dispersed rural areas of the country. We therefore decided to initiate a process of health reform to move the line of attack from the tertiary hospitals to primary care facilities to encourage the active participation of the general population in promoting healthy lifestyles for the prevention of cancer and other chronic diseases.

In this context, the Esperanza Plan was developed, with the aim of improving the geographical and cultural access to the supply of services in health promotion, prevention, early diagnosis, final diagnosis, staging and recuperative and palliative treatment of cancer for the entire population. In addition, the Plan aims to achieve a progressive and sustained increase in the response capacity of the public sector by investing in trained human resources, infrastructure, equipment and supplies, and seeks to improve economic sustainability by joining the public security and the allocation of financial resources for the Plan. So far this year, we have managed to train 661 professionals in primary and secondary cancer prevention, 656,163 people have been screened, 117,498 families have been educated about cancer risks in 18 regions of the country and 4,320,143 people have been exposed to cancer prevention across the country.

### 3. Panel discussion: Linking cancer, NCD control plans and communities

*Andreas Ullrich, WHO; Edgar Amorin, COLAT; Miguel Garavito, FISSAL; Tatiana Vidaurre Rojas, INEN; Francisco Tejada, University of Miami*

In May 2013, the Global Action Plan for NCDs was adopted at the Sixty-sixth World Health Assembly and defined priorities for prevention and control for the next seven years (5). We now have a global agenda for cancer and other NCDs that will challenge the health community to collaborate and integrate their individual agendas and plans. The plan is driven by the fact that there are many common risk factors for NCDs, including cancer, and we therefore have the opportunity to synergize our efforts for prevention and control. This will require members of the different disease and risk factor communities to collaborate and learn from each other. For example, much work has been done in the tobacco community around laws and regulations and prevention, leading to the development and adoption of the WHO Framework Convention on Tobacco Control (14). This approach has succeeded in changing norms surrounding smoking in many countries and may provide insights that could be applied to control other risk factors. Tackling NCDs will require a multisectoral approach involving all sectors of society, including governments, civil society, industry, academia and nongovernmental organizations. Within government, all departments will need to be involved and health will need to be considered in all policies. Within academia, methods for training medical professionals will need to evolve to adapt to the changing paradigm for NCD prevention and control, with more emphasis on primary and community care and fostering health rather than treating disease. Ultimately we need to educate the population and communities around health issues as long-term success in preventing disease requires community engagement.

#### Workshops

##### 1. Individual and provider-level interventions to reduce cancer risk

*Graham A Colditz, Washington University in St Louis, USA and Javier Manrique-Hinojosa, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru*

While many cancer prevention endeavours focus on aspects of behaviour change at the individual or community level, shared experiences across groups can reinforce lessons learned and opportunities to deliver a more integrated approach to prevention. Provider-level interventions can both

reinforce prevention messages and increase attention to prevention among those receiving care. Providers serve as opinion leaders in many communities and engaging them in prevention magnifies the potential impact of prevention messages. Examples from many countries can inform strategies to increase the reach of prevention. This workshop aimed to share experiences and speed the adoption of strategies that would harness the power of prevention.

**Abstract 1: A professional education programme on cervical cancer prevention: The results of an e-learning experience**

*Francisco J Bosch, José M Borrás, Patricia Pérez, Assumpta Company, Ana Sedano and Mireia Montserrat, Institut Català d'Oncologia (ICO), L'Hospitalet de Llobregat, Barcelona, Spain*

**Background**

Cervical cancer remains the second most important cancer in women worldwide and the cancer priority in most developing countries. It is largely preventable and, if diagnosed and treated at an early stage, is a highly curable disease. In the absence of efficient preventive action, it is usually diagnosed in advanced stages and results in a major cause of death among young women. The advent of HPV vaccines and the impact of screening represent a milestone in our opportunities for prevention. The introduction of a new vaccine targeting women worldwide requires that literally tens of thousands of health professionals and decision-makers understand its value and mode of use. A virtual course has been designed to provide such information to health professionals worldwide without costs for the participant.

**Objectives**

- ▶ Create and promote an e-learning educational programme on HPV and cervical cancer epidemiology and prevention suitable for a wide audience of health professionals;
- ▶ Create an international network of professionals qualified as key trainers in cervical cancer prevention in critical countries.

**Results**

The Project was supported by various unrestricted educational grants. The technological platform and the scientific and pedagogical methodology were provided by e-oncología, the e-learning platform from Catalan Institute of Oncology (ICO), Barcelona, Spain.

The output was an 18-hour distance-learning course in Spanish, English, French and Russian. The contents are largely based on the ICO HPV Monograph series. The

programme was scientifically validated and endorsed by FIGO, UICC, IAEA, IARC and WHO, and is being freely distributed. Since 2011, more than 8,000 professionals worldwide have registered for the course, a pool of 32 international tutors have been certified and acted as course professors in their own environment, and 70% of the students have been certified.

**Conclusions**

E-learning methodology with tutorial support can be a good and affordable solution to the medical education in low-income countries and the contents are easily adapted to each country.

**Abstract 2: Cancer Prevention Center: Nine years of experience in health promotion, cancer prevention and early detection**

*Alice M Zelmanowicz, Dayane A Cicolella and Livia L Campo Irmandade Santa Casa de Misericórdia de Porto Alegre, Porto Alegre, RS, Brazil*

Cancer is a public health problem due to the high death rates and incidence. The Brazilian southern region shows the highest rates of new cases. Prostate and breast cancers are the most frequent. Preventive activities are necessary for cancer control. In 2004, the Center for Cancer Prevention (CPC) at Irmandade Santa Casa de Misericórdia de Porto Alegre was created. The CPC is a medical complex of seven hospitals with multiple medical specialties. Through actions towards prevention, education and health promotion, CPC offers assistance and raises people's awareness about individual health. It promotes actions related to changes in attitude and habits that act as precursors to sickness. Each medical specialty develops specific actions and interventions towards the risk factors that act in the health-disease process. Currently the multidisciplinary team is formed by 37 areas: gynaecology, geriatrics, dermatology, mastology, endocrinology, cancerology, head and neck surgery, oncology surgery, urology, coloproctology, gastroenterology, genetics, nephrology, fertility preservation gynaecology, stomatology, nursing, nutrition and psychology. It has an area for health education where there is an exhibition of educational materials in the waiting area. The Center serves an average of 700 outpatients per month with a 98% satisfaction rate. More than 37,200 consultations have been carried out (2005–2013). Lectures are offered to the community, encouraging a change in attitude. Annually a bigger event celebrates the National Day for Cancer Prevention (27 November). It is estimated that 28,000 people have been reached by the educational actions carried out by the CPC.

Different means of communication are used. During these nine years, a lot was invested in the production and distribution of more than 100,000 leaflets (according to the annual budgets). It is considered that actions developed by the CPC contribute to the authentication of a healthy lifestyle as a way to impact on cancer incidence and mortality in our milieu.

*Abstract 3: Tips and lessons learned from an established population health-based primary cancer prevention programme*  
*Sonia Lamont, British Columbia Cancer Agency, Vancouver, BC, Canada*

The evidence base shows that more than 50% of cancers are preventable by implementing the healthy lifestyle choices that are known about today. But what might a primary cancer prevention programme in action look like and could such a model be scalable and flexible enough to be applied in various settings? Tips and applicable lessons learned from an established, population health-based programme of cancer prevention work in action will be presented. Whether small or large steps in cancer prevention are possible in the work that you do, the lessons learned will have something for you.

Bringing a provincial and regional lens to cancer prevention, the British Columbia Cancer Agency Prevention Programs (BCCAPP) takes a population health community-based approach to promoting and educating the public and others about cancer prevention and healthy lifestyle choices. This work is done in partnership with regional health authorities, nongovernmental organizations, community groups and other cross-sectoral entities. BCCAPP promotes and educates those located in urban, rural, and/or remote environments and within diverse populations such as the Aboriginal, Chinese and south Asian communities. A key facet of BCCAPP is the well-networked provincial front-line staff who work with pre-existing community groups to initiate risk factor behaviour change in a supportive environment. A recently published book, *Community-based prevention: reducing the risk of cancer & chronic disease* (15), overviews this and other similar international models.

The BCCAPP's award-winning programme focuses on the five main preventable risk factors critical to cancer prevention (tobacco use, excess weight, poor diet, inactivity and excessive sun exposure). Many of these risk factors also significantly impact on chronic diseases such as diabetes and heart disease.

Though not without obstacles, such as securing long-term financing and a virtual team spanning vast geographical

distances, BCCAPP's model enables it to continue providing evidence-based information to communities for group-supported action in a maintained and sustainable manner.

#### Box 1: Summary and recommendations from Workshop 1

##### Challenges

- Measuring the impact of interventions – outcome measures can be difficult to define and collect
- Sustaining engagement and interest in common prevention priorities across sectors

##### Recommendations

- Need better strategies to raise provider awareness about the importance of prevention
- Need consistency of communication by providers in messaging around healthy lifestyles

## 2. Community-based interventions to reduce cancer risk

*Neal Palafox, University of Hawaii, Honolulu, USA, and Gustavo Sarria-Bardales, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru*

It is within a community that behaviours which reduce or enhance cancer risk begin, are reinforced and are sustained. The community, its culture, its environment and its members' participation in health behaviours are therefore the most significant determinant of cancer outcomes. Effective community-based interventions to reduce cancer cannot simply be placed in a community, but must be developed with the community and become the norm of the community.

There are existing programmes that have demonstrated how communities have utilized their social, cultural and stakeholder assets to ensure that cancer and NCD interventions are effective and sustainable. Participatory community engagement and partnership with government, academic and research partners are crucial components of effective and sustainable programmes.

Community-based interventions that are based on a participatory framework, work to build community capacity, engage communities as an equal partner and make the community an essential component of problem solving are likely to meet with the most success. Community well-being and development should be at the centre of any community-based intervention to reduce cancer risk.

*Abstract 1: Training for trainers in cancer prevention counselling*  
*Abel Limache-García, Gustavo Sarria-Bardales, Javier Manrique-Hinojosa, Miguel Ruiz-Ninapaytan, Dahjana Arce, Carmen Carpio and Tatiana Vidaurre Rojas, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru*

### Introduction

Cancer and other chronic degenerative diseases are currently a growing cause of incidence and mortality rates in many countries, and particularly in developing countries like Peru. One of the important factors for the prevention and control of cancer is the education of the general population, so it is important and necessary to train health and educational professionals to disseminate recommendations and counselling related to cancer prevention, focused on tobacco control, physical activity, infections (e.g., HPV, *Helicobacter pylori*, hepatitis virus), and screening and early detection of the most common cancers in our country, including cervical, breast, stomach, lung and prostate cancer.

### Target

Train health professionals and teachers in methodologies about cancer prevention and early detection through prevention counselling.

### Methodology

The Department of Health Promotion, Prevention and Cancer Control of INEN coordinates with the regional health directorates of the regional governments to select the medical professionals and nurses who will receive ongoing training workshops for cancer prevention counsellors. The cancer prevention counsellors are committed to completing the course of training, training other health professionals and offering cancer prevention counselling in their regions. For the training course, guides and flipcharts were developed for cancer preventive counselling.

### Results

Since 2011, we have trained 4,640 professionals who have provided cancer preventive counselling to more than 100,000 individuals throughout Peru. The first trainers have developed more than 150 courses to train other trainers.

#### *Abstract 2: INCA: Opening doors to high schools*

*Suse D Silva-Barbosa, Luciane S Soares, Luiz C Thuler, Marisa D Breitenbach, Anke Bergmann and Luis Felipe R Pinto*

*National Cancer Institute, Rio de Janeiro, RJ, Brazil*

Cancer is an enormous public health problem in Brazil and many strategies have been used to improve the quality of life and health of the population. To address this issue, a social project was organized and conducted by postgraduate students, researchers, physicians and providers in health education, all of them from the National Cancer Institute (INCA) in Brazil. The basic concept of this

concerted project was that “the most effective treatment for cancer is to prevent the disease”.

Assuming that school provides an adequate social environment to diffuse and amplify information, we organized an interdisciplinary programme to provide information about cancer prevention to teenagers from public schools in Rio de Janeiro.

Initially the postgraduate students involved were trained to disseminate information about cancer. The objective was to provide support for people whose background was in science and technological research, helping them to acquire the skills necessary to disseminate information about cancer.

The pilot project was conducted at Tim Lopes School where postgraduate students shared their experiences with 300 high school students between the ages of 14 to 18 years. The project included discussions about risk and lifestyle factors related to cancer incidence and practical activities using games as a strategy to be more engaging and stimulate feedback.

After that, some students were selected to visit INCA facilities. This supplementary activity was to show them state-of-the-art cancer research and encourage them to see health research as a future career.

The programme represents a diverse workforce and its partial evaluation was very positive. For now, future directions include: to identify risk-based priorities related to the local context and to adapt the programme accordingly; to incorporate more schools from the same area; and to elaborate good practices to measure whether an effective intervention has been implemented.

#### *Abstract 3: Strategies of health promotion for cancer prevention:*

##### *The experience of INEN*

*Abel Limache-García, Gustavo Sarria-Bardales, Javier Manrique-Hinojosa, Miguel Ruiz-Ninapaytan, Dahjana Arce, Carmen Carpio, Melania Vargas-Orihuela, Julia Huaman, Marlene Fierro, Maria Luisa Trelles and Tatiana Vidaurre Rojas*  
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##### *Background*

Health promotion for cancer prevention is an important component of cancer control. Information, education and communication are principle strategies in health promotion. In this way, the Health Promotion, Prevention and National Cancer Control Office of INEN has initiated activities to focus on cancer prevention through changes in lifestyles and to motivate the population to make decisions about their health.

### Objective

To improve the knowledge of the community and increase people's capacity to make decisions about maintaining a healthy lifestyle through promoting cancer prevention and detection.

### Methodology

The community has been educated by two strategies:

- ▶ **Education session:** Before personalized counselling, people must attend an education session – a conference where the speakers are physicians and nurses who talk about cancer, risk and protective factors, and healthy lifestyles and invite them to attend personalized counselling.
- ▶ **Personalized counselling:** Each person receives approximately 25 minutes of counselling by trained nurses where they are provided with specific information on cancer prevention and early detection; they use brochures, pictures, flipcharts and guidelines on cancer prevention, which have been adapted to our culture.

### Results and conclusion

During the last 10 years we have provided education sessions every Friday of each week from February to November and more than 32,000 people have attended. Since 2011, we have implemented cancer prevention and control planning and 4,000 people have also received personalized counselling. We consider that this experience allows them to change their lifestyle, to know how to prevent and detect the most important cancers and to share

the information with other people in their communities. The education and personalized counselling sessions are very important strategies in the cancer prevention and control programme, especially in low- and middle-income communities, and we hope that they will contribute to cancer control in our region.

### 3. Policy-based interventions to reduce cancer risk

*Andreas Ullrich, World Health Organization (WHO), and Roxana Regalado, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru*

#### What we know

With more than one third of the overall cancer mortality explained by external causes, modifiable risk factors are the most promising targets for cancer control strategies and programmes. A wide variety of modifiable factors influence cancer risk, including behavioural (e.g., tobacco use, physical inactivity, unhealthy diet, obesity and alcohol use), infectious (e.g., HPV and HBV) and environmental and occupational (e.g., asbestos, arsenic, diesel smoke) exposures.

#### The challenge of modifying risks

Modifying cancer risks in a way that impacts the burden of cancer will require substantial changes to many sectors of society, including the production and advertisement of goods, tobacco demand and supply, urban planning and health system development.

#### The role of WHO and the paradigm change in global health

Over the last decade, WHO has developed global strategies to reduce exposure to behavioural factors that influence the risk of cancer, including strategies to reduce tobacco consumption (WHO Framework Convention FCTC (14)), to increase the adoption of a healthy lifestyle (global strategy on diet and physical activity (16)), and reduce alcohol consumption (WHO Global Alcohol Control Strategy (17)).

These policies combine interventions at the national level (e.g., taxation of tobacco), the community level (e.g., increased availability of options for physical activity) and the individual level (e.g., smoking cessation treatment, vaccination against HPV and HBV, and screening for cervical cancer). In implementing the UN High Level NCD Declaration, the Sixty-sixth World Health Assembly (2013) agreed on an NCD action plan which combines all of these risk reduction strategies and complements it with a health system-strengthening approach with a major focus on primary health care service delivery (5).

#### Box 2: Summary and recommendations from Workshop 2

- ▶ Involve the municipal level of government in the design, creation and implementation of community-based interventions
- ▶ Use mass media to educate the community and create favourable conditions for engaging the community in cancer control
- ▶ Identify and involve strategic sectors (teachers, church, youth, universities) in engaging the community
- ▶ Value and treat the community as an equal partner in designing, creating and implementing interventions
- ▶ Create a "social audit" to monitor programmes and empower communities (Social audit: level of knowledge and confidence of communities in interventions)
- ▶ Use short-, mid- and long-term outcome and process measures when evaluating impact
- ▶ Build community capacity through technical support (methods, ideas, design) with specific roles for each community stakeholder
- ▶ Develop supportive environments for the community in academic/government institutions

*The role of national governments*

These strategies and the NCD action plan are the result of broad consultations with governments, nongovernmental organizations (civil society) and the private sector. All of the strategies have been agreed upon by WHO Member States as World Health Assembly resolutions which give WHO Member States (national governments across sectors: Ministries of Health, Agriculture, Finance, Labour, Urban Planning and Traffic) and civil society roles and responsibilities in implementing these strategies to reduce cancer risks and to increase health system capacity for NCD prevention and control. Many countries are starting with national NCD strategies and plans which follow WHO's technical guidance in NCD prevention and control.

*The NCD agenda and the challenge of linking it to cancer control*

In 2011, heads of state at the UN High Level Meeting on Noncommunicable Diseases agreed on an NCD declaration and proposed a paradigm change to the global health agenda by asking for urgent action to combat NCDs. This change in vision to reduce NCDs stems from the premise that cancer, CVD, diabetes and obstructive lung disease are most effectively dealt with as a "package", with a focus on controlling behavioural factors and strengthening health care systems. One rationale for taking a combined approach is that there is broad overlap of risk factors between cancer, CVD, diabetes, and lung disease (e.g., tobacco for CVD and cancers, unhealthy diet/obesity for cancer and diabetes). The underlying model of the NCD agenda, however, very much favours CVD control and reduction of CVD risk factors at a population (e.g., salt reduction) and individual level with a primary health care approach (e.g., treatment of hypertension and hypercholesterolemia). This is because reducing cancer risks is more complex with more factors to be addressed, and reducing individual risks requires more investment in health care delivery (e.g., cancer screening and linking screening to secondary and tertiary care treatment).

The workshop addressed the following areas of work:

- ▶ Setting national/community priorities in cancer risk reduction: behaviour versus infectious versus environmental causes.
- ▶ Roles of government, civil society and the health care system.
- ▶ Synergies between cancer and NCD risk reduction: how to link to CVD, pulmonary disease and diabetes initiatives and achieve win-win situations.
- ▶ How to identify non-behavioural cancer risks (e.g., infections and environmental risks) and liaise with the

infection control/vaccine and environmental communities.

- ▶ How to position cancer screening programmes in national priority setting and community implementation given that screening programmes are unique to cancer in the NCD agenda.

*Abstract 1: Strategies of health promotion to cancer prevention: The experience of INEN*

See abstract under Workshop 2

*Abstract 2: Tips and lessons learned from an established population health-based primary cancer prevention programme*

See abstract under Workshop 1

*Abstract 3: Children's social representations of smoking: A photovoice project in Petrópolis, Rio de Janeiro, Brazil*

Rodrigo S Feijo, National Cancer Institute, Rio de Janeiro, RJ, Brazil

Smoking is the main risk factor, after high blood pressure, for noncommunicable diseases which are responsible for 63% of all deaths around the world. Despite successful smoking control policies implemented in Brazil, data shows that the prevalence of students that have ever smoked cigarettes is higher than 50% in many cities. Children's knowledge is often neglected when policy-makers design public health programmes. The general aim of this research is to contribute to the development of tobacco strategies focused on children by assessing their social representations of smoking using the photovoice technique with students from Petrópolis, Rio de Janeiro, Brazil. In total, 27 children (15 girls and 12 boys) between the ages of six and 16 years took part in the project that involved taking pictures, writing essays and group discussions. Children participated in three meetings over a period of 15 days. Thematic network analysis was performed to examine the data. Findings suggest that children's representations of smoking are very complex and controversial. While at first sight representations may be negative, with children highlighting many health risks related to smoking, after some interaction they also point out positive aspects of smoking that can make them experiment with cigarettes and later become smokers themselves. In practice, the research suggests that any programme aiming to prevent children from smoking will need to be very comprehensive and interact with other tobacco control initiatives, such as those which provide smoking treatment to children's family members. This is the first study of children's social

representations of smoking in Brazil and further research needs to be carried out.

#### Box 3: Summary of Workshop 3

- ▶ All actors – individuals, family, community, institutes and government – play a role in cancer control
- ▶ All actors need to be invested and engage in the guidelines for cancer prevention for them to be successful
- ▶ Priorities for cancer control differ by context
  - Whatever the context, when decisions are made it is important to take action immediately
- ▶ Synergies between prevention for NCDs and cancer exist (shared risk factors in nutrition, smoking, healthy lifestyle, etc.)
  - Policies promoting a healthy lifestyle should be pursued

#### 4. Regional interventions to reduce the risk of cancer

*Francisco Tejada, University of Miami, USA, and Milton Soria Humerez, Instituto Nacional de Laboratorios en Salud, Bolivia*

This workshop explored interventions that can be implemented at a regional level to reduce the risk of cancer and noncommunicable diseases (NCDs) at all levels of the health system and society. The current sociocultural environment of our communities, appropriately called the social determinants of health, promote the development of cancer and other NCDs and their sequelae. The traditional curative and recuperative interventions of medical and health care systems are stabilizing these increases in developed countries, but cancer incidence and mortality continue to increase in many developing countries. The interventions needed to decrease the risk of cancer and NCDs require complex interdisciplinary, multidisciplinary and multisectoral actors and actions addressing the social determinants of health as well as health and medical care systems. These interventions need to be evidence-based and adapted for efficient dissemination in the region.

The oral abstracts selected for presentation in this workshop highlighted the complexity of these interventions and can be seen as models or frameworks for similar preventive actions and interventions that can be expanded to the region. The roundtable discussions following these oral presentations addressed the following questions:

- ▶ How do you measure the incidence and prevalence of risk factors for cancer and NCDs in your area/country? Are there multiple registries (i.e., hospital, public health units/departments), a national registry or periodic population surveys? How could this system be improved?
- ▶ In your area/country what interventions have been implemented to control risk factors for cancer and

NCDs? How successful have they been and how has success been measured? If they have not been successful, what challenges were identified and how can they be overcome?

- a. Thinking about the successful interventions, what characteristics do they have in common that have led to their success? (e.g., multiple components, action on multiple levels, integration with other interventions and services).
  - b. What additional interventions would you recommend implementing in your area/country? What challenges do you see to their implementation and how can these be overcome?
- ▶ What successful interventions in your country could be disseminated or expanded to other areas/nations or the region? Are they portable and adaptable? What interventions to reduce the risk of cancer and NCDs are being applied at a regional (Americas) and/or global level? What factors or characteristics contributed to their dissemination and adoption at the regional or global level?

#### *Abstract 1: Lessons for cancer control from an STI population-level intervention*

*Patricia J Garcia, Universidad Peruana Cayetano Heredia, Lima, Peru*

The PREVEN trial was a joint effort between the Universidad Peruana Cayetano Heredia, the University of Washington and Imperial College, London. It was designed as a community randomized trial of a multicomponent intervention for the prevention of sexually transmitted infections (STI) in Peru. The study was conducted in 20 Peruvian cities with populations of 50,000 to 300,000; 10 of which were randomized to intervention and 10 to control conditions. The intervention was comprised of three main components: (1) intensive outreach through a mobile team (health provider and peer educator) to female sex workers (FSWs) offering STI testing and treatment, condom promotion and promotion of health services; (2) the development of a referral network of pharmacies, midwives and physicians to strengthen syndromic STI management and prevention of STIs in the general population (the PREVEN Network); and (3) a social marketing campaign also aimed at the general population to enhance recognition of STIs and condom promotion. The intervention ran for three years and was evaluated through baseline and two- and three-year follow-up surveys, including STI testing, among convenience and time/location samples of FSWs and three-

stage random cluster household samples of 18–29 year-olds in the general population. Results showed a 34% reduction of STIs among FSWs and a 23% reduction among general population heterosexual women exposed to the intervention.

Several pertinent lessons can be derived from this important and successful trial which could and should be taken into consideration for cancer prevention: (1) the importance of collaboration of different entities (international and national); (2) the development of multicomponent interventions; (3) the inclusion of different health providers (including “informal sector”, such as pharmacies, in prevention activities; and (4) the inclusion of well-designed evaluation strategies, including the collection of baseline data.

**Abstract 2: Contribution of the Peruvian Commission Against Tobacco (COLAT PERU)**

*Abel Limache-García, Luis Pinillos-Ashton, Carlos Farias-Alburqueque, Carmen Barco-Olguin and Mercedes Quesquen-Puente, Comisión de Lucha Antitabaquica-Coalición Multisectorial Peru contra el Cáncer, Lima, Peru*

Smoking is a public health problem; tobacco use is responsible for one in three cancer-related deaths. The tobacco industry has developed different strategies to increase its consumption, including false and immoral advertising and the creation of unreal social responsibility. In Peru before 1985, tobacco consumption was allowed everywhere, more than 95% of teenagers ignored the risks of smoking and there was no awareness of tobacco as a public health problem.

The Peruvian Commission Against Tobacco was created in 1985 and the first step was to raise awareness of the problem through social mobilization. We organized concerts, long walks, bicycle and running events, musical festivals and the planting of 1,000 trees in one minute. We coordinated with the Ministry of Education to include in the school curricula information about “The pleasure of not smoking”. We coordinated with governmental institutions to create cessation programmes, information campaigns and through advocacy actions, such as a meeting of past Ministers of Health, we promoted laws to prohibit smoking in public places.

In 2004–2005, two events helped tobacco control: (1) Peru signed the Framework Convention on Tobacco Control and a multi-sectoral coalition against cancer was created with the participation of the public and non-public sectors; and (2) our Commission integrated the coalition and

promoted a new law according to the Framework Convention.

The actual law prohibits smoking in public places (100% free from smoke), mandates that graphic warnings be placed on both sides of the pack and imposes other regulatory standards according to the Convention on Tobacco Control. Currently the risk of smoking is known, there is respect for non-smokers and the law is enforced.

The “Day of Non-smokers” was established (31 May) and opinion leaders were engaged.

Now we are working to eliminate all tobacco publicity, increase tobacco taxes and improve cessation services. Health and tobacco control for all and by all.

**Abstract 3: Clinical, epidemiological and genomic studies of *Helicobacter pylori*: The role of contaminated water**

*Manuel Valdivieso, University of Michigan, Bingham Farms, MI, USA; Chuanwu Xi, University of Michigan, Ann Arbor, MI, USA; Alejandro J Bussalleu, Universidad Peruana Cayetano Heredia, Lima, Peru; Italo Novoa, Universidad Peruana Cayetano Heredia, Lima, Peru; Blga Soledad Osorio, Division General of Environmental Health of the Ministry of Health of Peru, Lima, Peru; Rachael Sexton, SWOG Statistical Center, Seattle, WA, USA; Kevin F Boehnke, University of Michigan, Ann Arbor, MI, USA; John J Crowley, SWOG Statistical Center, Seattle, WA, USA; Gary E Goodman Swedish Medical Center Cancer Institute, Seattle, WA, USA; and Laurence H Baker University of Michigan, Ann Arbor, MI, USA*

Gastric cancer (GC) is the most common cancer and cause of cancer death in Peru. *Helicobacter pylori* (HP) is a carcinogen type I and is associated with GC. We hypothesized that water contamination by HP could contribute to the large number of cases of GC throughout Lima. We investigated the relationship of gastric infection by HP to the presence of HP in patients’ drinking water and its associated biofilms, by culturing methods, quantitative PCR HP-specific DNA and correlations with water characteristics including residual chlorine. In total, 182 symptomatic patients were screened; 177 are analyzable; 106 tested positive by gastric biopsy. Of these, 89 HP positive patients come from high-risk, low-socioeconomic areas; 70% were females and 87% were older than 40 years. All laboratory studies ran concurrent controls. Quantitative PCR found HP-specific DNA (CN/mg tissue) present in 55 of 71 HP gastric biopsy negative (range, 9.69 – 294952.44) and in 94 of 106 HP gastric biopsy positive patients (range, 29292.24 – 1798528.08). Corresponding water levels (Copies/L) were 0-3365000, being lower in their biofilms: 0-68600. There were no

correlations with district of residency, water source, crowding and chlorine in the water. We could not culture HP from water though our developmental culture efforts continue. A positive response to treatment by urea breath test (UBT) at 6–8 weeks was 70%. There is evidence of HP in the drinking water of Lima and in symptomatic patients with and without biopsy evidence of HP.

#### Box 4: Summary of Workshop 4

- Understand the problem! There is a need for epidemiology and formative research
- Include multicomponent interventions
- Collaborate with different entities (international and national)
- Detailed planning and involvement with the authorities and community is critical
- Involve different types of health providers, also “non-traditional” sectors (e.g., drugstores)
- Provide training, certification (recognition), support and monitoring - Create networks. Identify champions
- Create awareness campaigns to engage the community
- Ensure services are ready to respond
- Include both prevention and management and ensure good coverage
- Measure outcomes – inclusion of well-designed evaluation strategies is key

PLUS: Research to validate interventions

## Discussion and conclusions

*Graham A Colditz, Washington University in St Louis, USA and Eduardo Cazap, SLACOM, Argentina*

This session drew attention to the importance of awareness and communication with providers of prevention messages. Many preventive services begin with the primary care provider and their engagement and endorsement can reinforce broader prevention programmes delivered in the community. Beyond providers, involvement of all interested stakeholders in cancer prevention is necessary to reach all members of society. Delivery of messages that are accessible to all levels of education is needed in the locations where the population is to be influenced. One strategy is point of sale advertising as used for marketing by many commercial products (including, historically, tobacco sales, sugar-sweetened beverages, etc). Prevention needs similar strategies to promote wellness.

When delivering prevention messages, whether through providers or in the community more broadly, tailoring these messages to the community is an important component of inviting participation in prevention. To maximize the benefit of prevention messages, and the opportunities for prevention, we

must broaden the range of providers and services to deliver prevention. Schools offer one important component for nutrition and physical activity, for example. Here, teachers are not typically thought of as cancer specialists, but through multiple aspects including the curriculum, school lunch and physical education, the school system and its staff offer opportunities for prevention.

To increase the efficiency of prevention programmes, we need evaluations that quantify aspects of the process, performance and impact of prevention messages and interventions (18, 19). Such evaluations could include a social audit as one performance measure. Evaluation must take the broader time horizon that corresponds to the development of cancer and the time frame for preventive interventions to pay off (8, 20). For example, infant vaccination with hepatitis B vaccine will prevent liver cancer many decades later. But monitoring the level of delivery of vaccination is necessary throughout the development and delivery of a vaccine-based prevention programme. Thus, evaluation must define short-, intermediate- and long-term measures of implementation and outcome success for prevention. Clearer definitions of appropriate measures will help bring more consistent prevention for cancer and other NCDs.

Prevention is implemented in the context of communities and these environments must be engaged in the process of priority-setting and evaluation. Providers, academics and government policy-makers must come together with communities to define common targets for prevention and acceptable measures of progress.

To achieve cancer prevention, we must not just convene and make recommendations, but rather we need to institute actions and ensure the capacity for response is present across all aspects of society, and that the measurement and reporting of interventions is instituted as an essential aspect of programme development and delivery.

#### Acknowledgments

*This manuscript is a synthesis of plenary presentations, workshop discussions (including selected abstract presentations) and recommendations for ongoing actions derived from Session 1 of the Fifth International Cancer Control Congress (ICCC-5) held in Lima, Peru, 3–6 November 2013. The ICC-5 working group was made up of Simon B Sutcliffe, Kavita Sarwal and Catherine G Sutcliffe from the International Cancer Control Association and Tatiana Vidaurre Rojas and Roxana Regalado from the National Cancer Institute (INEN) in Peru. The opinions expressed herein represent those of the authors alone and do not necessarily represent the institutions and organizations by which they are employed.*

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THE FIFTH INTERNATIONAL  
CANCER CONTROL CONGRESS

SESSION 2:  
MOBILIZING “ALL OF SOCIETY”  
FOR EFFECTIVE CANCER  
CONTROL

# SESSION 2: MOBILIZING “ALL OF SOCIETY” FOR EFFECTIVE CANCER CONTROL

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The overall goal of mobilizing “all of society” for effective cancer control is to advance an inclusive societal movement that serves to educate, raise awareness, engage and advocate for improvements in population-based cancer control. Such mobilization requires a focus on the roles and relationships of all health stakeholders, including patient and community nongovernmental organizations (NGOs), the general public, academia, health professionals, policy-makers, the media and the private sector. Session 2 of the ICCC–5 examined the various issues and challenges involved in this mobilization. Its objectives included:

- ▶ to identify and share best practices and opportunities;
- ▶ to better define the roles of different stakeholders;
- ▶ to highlight specific interventions useful for advancing progress.

Competitively selected case studies from the Latin America region and elsewhere, expert plenary discussion and multi-stakeholder roundtable discussions were analyzed. It is clear that mobilizing “all of society” for effective cancer control requires a clear vision and the creation of a political conscience whereby health is perceived as a basic human right and the general public involved as socially aware and active citizens. Structures for the active involvement and engagement of “all of society” are required as is the need for advocacy and engagement to be based on robust evidence. Effective integration of the different sectors is crucial as well as integration and communication across regions and constituencies. Coalitions and networks are effective working models used among various stakeholder groups. Social media use and the harnessing of new technologies are enhancing networking and enabling work across regions allowing for increased mobilization of stakeholders and the general public at a low cost and at a magnitude not observed before. With increased political conscience and active engagement of NGOs, advocacy is seen as an essential part of effective cancer control, with social audit providing a means of measuring performance of population-based cancer control interventions.

*Key words: advocacy; awareness, mobilization, all of society, cancer control, patient organizations, nongovernmental organizations (NGOs)*

## Introduction

*Cristina Parsons Perez, Catalyst Consulting Group, London, UK, and Eva Maria Ruiz de Castilla Yabar, Esperantra, Peru*

Cancer currently kills over 8.2 million people a year with 64.9% of these deaths occurring in the less developed regions of the world (1). The disease is placing a strain on fragile and weak health systems and new cases cost the global economy over US\$ 286 billion a year (2). Cancer impacts each individual patient, their families, communities and society overall. It is impossible to account for the human pain and suffering caused by this disease. Effective cancer control is a moral imperative in a society equipped with the knowledge on how to prevent a third of cancers, how to treat and cure a further third of cases and how to palliate the remaining third.

The UN Political Declaration on the Prevention and Control of Non-communicable Diseases (NCDs) (3), created in September 2011, is a powerful tool for international cooperation and action and has afforded unprecedented global political momentum for effective cancer control. We are currently witnessing a paradigm shift where cancer is no longer perceived as a disease exclusive to rich and developed regions but is seen as a development issue, impacting the sustainable growth of nations. The UN Political Declaration has led to the creation of the WHO Global Monitoring Framework (GMF) on NCDs (4) with its comprehensive set of voluntary global targets and indicators including the historic target to reduce overall premature deaths from NCDs by 25% by 2025. This represents the first set of global targets on the four main NCDs (cancer, diabetes, cardiovascular disease and chronic respiratory disease) for which all governments are accountable and must report progress. The mortality reduction target poses a unique opportunity as well as a global challenge to the cancer community and broader society. Meeting it will require an unmatched and concerted “all of society” approach.

The Latin America and Caribbean region is well poised to take advantage of the global momentum generated on cancer and NCDs. In fact, the Caribbean region was the original instigator and motor behind the creation of the UN High Level Meeting on NCDs and its resulting Political Declaration. The Latin America and Caribbean region benefits from the following advantages and opportunities for increased regional action and coordination in cancer control:

- ▶ PAHO leadership and member states have stipulated NCDs are a priority issue for the region with a focus on multisectoral policies and partnerships.

- ▶ The existence of platforms for South–South political cooperation, such as UNASUR (Union of South American Nations) and its South American Health Council.
- ▶ The recognized need for resource sharing and regional cooperation in cancer control – as evidenced by the regional network of National Cancer Institutes (RINC).
- ▶ Civil society’s increased regional presence through numerous regional networks and coalitions.
- ▶ The existence of long-established North–South collaborations, such as those involving the CDC, US NCI and the American Cancer Society.

## Methodology and objectives

ICCC–5 Session 2 “Mobilizing ‘all of society’ for effective cancer control” comprised a panel discussion of recognized experts in cancer control followed by a question and answer session to provide an overview of the subject matter as a means of preparing Congress participants for participating in four, small group, interactive workshops on relevant topics to be addressed in greater depth. Selected abstracts providing particular insights into the topic area were presented orally by the authors in each of the workshops. Workshop leaders were encouraged to conclude their workshops with a brief set of prioritized recommendations to identify the key directions for further development of interventional activities beyond this Congress.

The objective of this session was to explore ways to meet global and regional challenges in cancer control through an “all of society” approach. The following four issues were selected for in-depth discussion in the workshops:

- ▶ patient advocacy for effective public policy;
- ▶ integration across regions and sectors;
- ▶ building a social movement;
- ▶ strengthening organizational capacity and networking.

## Panel discussion

### Creating and sustaining cancer movements: An “all of society” approach to cancer control

#### *Discussants and moderator*

Plenary speakers for this session included Andre Medici, World Bank; Dr Andreas Ullrich, World Health Organization (WHO); Dr Felicia M Knaul, Harvard University; Dr Eduardo Payet, University “Cayetano Heredia” of Peru; Professor Jose Gomes Temporao, Instituto Sul-Americano de Governo em Saúde (ISAGS-UNASUR) and ex-Minister of Health of Brazil; and Dr Maira Caleffi, Brazilian breast cancer oncologist and patient advocate. Dr Eva Maria Ruiz de Castilla, Esperantra Peru, and Dr Cristina Parsons Perez,

Catalyst Consulting Group International, served as co-chairs for the session, which was moderated by eminent oncologist and radio personality Dr Elmer Huerta.

#### *Panel discussion synthesis*

Effective cancer control requires a common understanding of ways to mobilize an effective “all of society” response to the growing challenges of cancer/NCDs. The expert panel discussion shared wisdom of the “how to”, “when to”, “which way”, and “what” of mobilizing media and the public opinion, attracting the interest of legislators, motivating policy-makers and holding decision-makers accountable, and boosting and legitimizing the role of civil society in advocacy and the realization of cancer outcomes.

Mr Andre Medici shared views on the socioeconomic dimensions of cancer with a focus on equity. It was noted that in Latin America out-of-pocket cancer costs are a major source of poverty and that the region’s public spending on cancer is mostly “curative” with an urgent need for increased investment in health promotion, prevention and early detection. Health systems in the region need to be organized around strong primary health care. Civil society holds an important role in signalling and vocalizing where public spending is needed while also maintaining shared service responsibility. Dr Eduardo Payet noted the importance of data and emphasized academia as a key social partner in the “all of society” approach to cancer control.

Dr Andreas Ullrich noted WHO is increasingly addressing cancer control from a horizontal and cross-cutting approach instead of the more traditional vertical (disease-specific) approach. This is particularly true for women’s cancers, with WHO groups working across technical areas to ensure issue integration and multiplication of expertise. This is the result of WHO visionary leadership and is a reflection of current trends in direction from member states. This trend may be reflected across the Latin America region with governments encouraged to increase health system efficiency while delivering improved health outcomes.

Dr Felicia M Knaul expanded on the importance of access to population-based cancer control programmes and the integrated development and strengthening of health systems. Central to the concept of health system strengthening is the “diagonal” approach to health care whereby disease-specific interventions and plans are integrated across horizontal platforms of care delivery with an important focus on primary care. Such diagonal activities were used with HIV/AIDS, with 10 to 15 years required to rearrange health systems to integrate HIV diagnosis, treatment and palliation into platforms such as poverty and

sexual and reproductive health programmes. A similar approach must be used in cancer control with cancer plans fully integrated into the health system. Strong legislated cancer plans with targets are needed as well as the accompanying regulation and local implementation. Monitoring and measurement of success over time is crucial and cancer control outcomes should be measured in line with global NCD targets such as the 25% reduction in NCD premature mortality by the year 2025 (4). Civil society has a crucial role to play in the public oversight of this success and in holding governments accountable for results. The human rights movement has been successful in establishing observatories to ensure that progress is monitored and violations or failures publicly reported, and this could be a model for cancer by civil society. A strong civil society protects against policy shifts with changes of government and can also help in building public support for necessary public investments towards meeting goals. Advocacy should be data-driven and research should be a target for advocacy efforts: “evidence-based advocacy and evidence based on advocacy”.

When analysing the requisites for mobilizing “all of society” in cancer control, Professor Temporao underlined the importance of understanding the process of building political conscience and framed health as a basic human right. He expressed the need for a collective movement to generate the notion of health as a right and that this must be underpinned by societal access to information and education. UNASUR views health as a key priority area, an essential social issue and a basic element of its formation. He cited RINC, the network of National Cancer Institutes, as an innovative example of international cooperation to address cancer control (5).

A crucial element of the “all of society” approach to cancer control is a strong and vibrant civil society with the patient voice at its core. Dr Maira Caleffi supported the notion that civil society in Latin America plays a key role as a watchdog of government’s actions and policies in cancer control and cancer outcomes. Increasing advocacy capacity in the region is resulting in patient groups increasingly working with the media to run campaigns mobilizing public opinion and demanding change. One example is the campaign “*O tempo corre atras* – time is running”, run by Brazilian breast cancer coalition FEMAMA, with a view to ensuring the implementation of a national law aiming for a maximum 60 days wait between cancer diagnosis and beginning of treatment (6).

The expert panel discussion agreed that civil society can and should be mobilized for cancer control purposes with a

clear vision and mission. Patient organizations and cancer survivors benefit, improve and enrich the process of health policy-making and deserve a “seat at the decision-making table”. Civil society must play the important role of “watchdog” of the political and health care system. Political conscience needs to be created and promoted in society. The resulting rewards are empowered citizens and empowered patients – pools of active grassroots advocates capable of mobilizing public opinion, influencing public policy and creating public demand for improved services and rights.

In final discussions, panelists reflected over key lessons for the Latin America region to improve cancer control. These can be divided into three main areas:

- ▶ **Partnerships:** Cancer control requires integration of work between all actors, including: governments, multilateral organizations, the private sector, academia, patient organizations, community-based organizations, professional societies, the media, and others. Cancer control needs to be cross-cutting across the different societal sectors as well as across the different government ministries. International spaces for cancer control convening and coordinating such as NCI, PAHO/WHO, UICC, UNASUR and RINC can be used to leverage increased cross-sectoral collaborations.
- ▶ **Health system strengthening:** Health systems are increasingly burdened by NCDs and there are opportunities for integration of health promotion and care into existing primary health care services.
- ▶ **Patient engagement and advocacy:** Governments need to ensure “all of society” engagement in cancer control. Brazil’s “Health Councils” are examples of health system monitoring structures and legal, institutional and social control. It is crucial that civil society be professionalized to take advantage of legal structures for social control.

## Workshops

### 1. Patient advocacy for effective public policy

*Cristina Parsons Perez, Catalyst Consulting Group International, London, UK and Mariella Pow Sang, Instituto Nacional de Enfermedades Neoplasicas, Peru*

Patient advocacy is a key driver of policy change towards improvements in patient treatment, supportive care and overall cancer control. For cancer control, civil society often initiates advocacy efforts by empowering patients, providing information, raising awareness and addressing individual, community and structural barriers to care (7). Empowered patients who can publicly share their experience contribute to breaking down the stigma of cancer and inspire others to

seek early detection, treatment second opinions, or demand access to services. Civil society in Latin America benefits from having social networks that can be leveraged for advocacy purposes, with both strong networks of committed volunteers as well as significant survivor communities. Breast cancer organizations have traditionally been the first cancer patient organizations leveraging such communities to politicize the individual disease experience with the aim of influencing public policy and driving systemic change. Adding advocacy to an NGO mission is a crucial step where change is sought for the majority as opposed to only a few. It is perhaps the most critical way of multiplying a patient organization’s impact although it requires resources, technical expertise, systems insight, a robust reputation and significant risk management skills. To effectively mobilize “all of society” in cancer control, civil society must be actively engaged in advocacy and to do so it is important to define the common elements observed in the development and maturation of advocacy efforts, some best practices currently being observed and what has worked to build grassroots movements capable of driving policy change.

*Abstract 1: Advocacy experience in Mexico and Latin America  
Bertha Aguilar and Begona Zabalza, Fundación Cimab, México  
DF*

The Cimab Foundation is an NGO with 11 years of experience fighting against breast cancer.

An important example of the Foundation’s involvement in shaping public health policy took place in 2009, when the official Mexican standard regulating the prevention, monitoring and treatment of breast cancer in Mexico (NOM 041) was subjected to revision. In this revision process, however, health authorities decided to move the age of routine breast screening from 40 to 50 years of age. This measure worried NGOs committed to the fight against breast cancer, which is why we organized a joint effort against this policy change. The first step was to launch an aggressive campaign directed at the Ministry of Health through Twitter. This strategy moved the officer in charge of revising the NOM to call a meeting with some NGO representatives to discuss the issue. The second step was to create a coalition formed by 18 NGOs, known as COMESAMA. This coalition successfully lobbied to maintain the age of preventive breast screening at 40 years, as well as to include 14 other recommendations. Two years after the publication of the NOM 041, the Cimab Foundation proposed the creation of a Citizen Observatory to evaluate the degree of implementation of this new official standard.

The Citizen Observatory will consist of surveys conducted among breast cancer patients in public hospitals and medical personnel (physicians, nurses, radiologists and directors of medical units). The collected information will be used to issue policy recommendations for improvement. The Cimab Foundation also belongs to a coalition of NGOs called Latin American Union Against Women's Cancers (ULACCAM), which is represented in seven countries in Latin America. This year, ULACCAM launched the "Declaration of the Rights of Latin American Women on Cancer" simultaneously in these seven Latin American countries, and we intend to obtain 10,000 signatures to position this initiative as a regional "Call to Action". It can be found at [www.ulaccam.org/declaratoria](http://www.ulaccam.org/declaratoria).

**Abstract 2: How a patient organization can influence access to treatment**

*Ignacio Zervino, Fundacion ACIAPO, Buenos Aires, Argentina*

The ACIAPO Foundation, founded in 1997, provides community assistance for oncology patients with public health insurance, including:

- ▶ emotional support;
- ▶ resources for their social needs;
- ▶ education about cancer prevention;
- ▶ advocacy;
- ▶ assistance for the growing number of patients;
- ▶ defending patient rights.

Because of the inefficiencies of the public health system and the delayed delivery of drugs (a situation that happens once or twice a year in Argentina), as a patient organization we focus on access. For years, we felt that our efforts were not strong enough and we needed to try something different, to put this problem on the public agenda. We decided to change our strategy, and finally chose the one that captured the most public attention. We have a cause and we needed to engage broadly to raise awareness. We needed high-impact actions to put pressure on public decisions, so we decided to develop and communicate using a Facebook site: "I am not receiving my treatment" (8). We started with our public and other patient associations, then continued with patients and relatives, and finally accessed the media.

**Results**

Immediate delivery of medication was normalized. Other consequences observed were:

- ▶ Stronger identity as a patient association with a focus on access.
- ▶ ACIAPO as a reference in terms of access in the whole

country.

- ▶ The success of this experience stimulated us to work on other issues, such as proposed law, the Biosimilar LA Patient Association and others.

**Abstract 3: Creating a civil society-led cervical cancer advocacy movement – the Caribbean Cervical Cancer Electronic Petition**

*Maisha T Hutton, Ian Pitts, Shivonne Johnson, Christopher Hassell, Gail Niles and Trevor Hassell*

*Healthy Caribbean Coalition, St Michael, Barbados*

**Background**

The Healthy Caribbean Coalition (HCC) is using the e-health platform to build public awareness and create social movements which drive improved cervical cancer policies and programmes. Caribbean Cancer NGOs launched the first ever Caribbean Cervical Cancer Electronic Petition (CCCEP) aimed at heads of government to increase Caribbean women's access to affordable cervical cancer screening. The Caribbean has the highest burden of HPV in the Americas. Cervical cancer is the second leading cause of cancer-related death in the region. The CCCEP builds on the successful 2011 "Get the Message" m-health campaign in which 700,000 people texted support for the UNHLM (United Nations High Level Meeting) on NCDs (3).

**Methods**

Twenty cancer NGOs representing 16 Caribbean countries developed the CCCEP. Objectives of the CCCEP were driven by the NGOs and based on regional priority needs around cervical cancer policy/programming. The e-petition is hosted on Facebook and collects: full name, email address, gender, age range, country of origin and mobile number. The signature target is 500,000. The petition is being promoted through social media, traditional media and mobile platforms. The final results of the petition will be presented to heads of government. The HCC is currently exploring regional mechanisms for the acknowledgment of e-advocacy.

**Results**

The CCCEP was officially launched on 11 June 2013. Ten days post-implementation, with minimal promotion, we have 995 signatories of which 85% are female. The age range of signatories is as follows: 33.2% are 18–30 years; 28.2% are 31–40 years; 19.4% are 41–50 years; 11.2% are 51–60 years; and 7.5% are 60 plus years.

**Conclusions**

In the coming weeks and months HCC will continue to

leverage resources and create opportunities to build awareness. The CCCEP is an important step in deepening the Caribbean democratic progress in which for the first time the people of CARICOM are seeking to directly influence cancer policy based on their own determination of priorities.

#### Box 1: Summary and recommendations from Workshop 1

- ▶ Working in coalitions and networks is an essential part of advocacy
- ▶ Utilizing social media is as an innovative way of getting advocacy messages across and for mobilizing grassroots support
- ▶ Advocacy can be an real enabler for governments instituting change

## 2. Integration across regions and sectors

*Paula Kim, George Mason University, Washington DC, USA, and Mariana Faria, Instituto Suramericano de Gobierno en Salud – Union of South American Nations (ISAGS-UNASUR) Rio de Janeiro, Brazil*

The growing global cancer/NCD burden heightens the challenging need for greater and more rapid country and region preparedness in cancer control and public policy. Mobilizing global “all of society” responses offers a compelling and logical response to meet this fast moving challenge and need. Successful mobilization relies greatly on effectively informing and engaging people across regions and sectors. However, very little data, information and guidance exists, whether evidence-based or anecdotal, on the “ins and outs” of exchanging ideas, knowledge and best practices locally, regionally or globally. Shared responsibility exists to promote and assist integrating and sharing methods across regions and sectors to sustain progress and educate and empower less advanced countries and organizations.

Productive sharing and integration depends on many variables including relevance to the region, resources and sociocultural and political contexts. There is no such thing as an ideal model or textbook approach, as one size does not fit all. Albert Einstein said it best with “information is not knowledge.” We must and can create better sharing and integration processes because even in this era of information and technology, they alone do not drive change or solve problems.

Experience learned becomes information shared or vice versa. Examples shared becomes knowledge gained and that powers movement and change. Every successful societal movement or programme was at one time just an idea, experience, vision or dream realized and led by the will of

very strong people.

History shows that an organized societal movement powered by passionate leaders equipped with shared information and experience is one of the most effective and powerful catalysts at prompting government action and changing attitudes. Very little, if any, meaningful progress will occur unless and until governments understand, legislate and fully support organized cancer/NCD control with appropriate and sufficient collaboration, leadership, financial and human resource support.

*Abstract 1: Alianza GIST: Building a coalition in Latin America  
Piga R Fernandez, Alianza GIST/Life Raft Group, Santiago, Chile*

Alianza GIST (AG) formed in 2009 with the goal of improving the survival of people living with a rare cancer called GIST (Gastrointestinal Stromal Tumour) in Latin America (LA), through scientific research, information, education and advocacy. The group is comprised of patient advocates from 14 countries aiming to close the gap between scientific knowledge and the clinical treatment of GIST, identify and educate more patients and key medical professionals, empower patients to take charge of their own care and improve access to safe and effective treatments.

AG works in collaboration with The Life Raft Group (LRG), an international GIST advocacy organization, in which the LRG helps to provide the scientific knowledge, technology and other resources to help AG accomplish their goals in the region. For example, the LRG runs a patient registry, from which data collected generates critical information about the GIST patient population and tracks important trends among this rare disease community. The registry was recently introduced in LA and serves as a tool to collect statistics of how many GIST cases are prevalent in LA countries as this information is not readily available through LA national cancer institutes. The LRG also hosts a tissue bank that allows AG to collect tissue and do free molecular testing otherwise unobtainable in the LA region. In the past year, 20% of evaluated tissues were misdiagnosed as GIST in LA.

The tools that the LRG has provided AG have strengthened their capacity to help patients survive. The information has helped the AG strengthen their educational and advocacy efforts among the patient and physician community. For example, a physician education CME course was implemented in collaboration with Monterrey TEC (Monterrey Institute of Technology), as well as a Tumor Board convened at ASCO. The goal was to help physicians across LA improve their knowledge of treating and managing GIST.

*Abstract 2: Over Cancer Together: Piloting a programme to build the capacity of Japanese cancer NGOs to improve patient-centred advocacy*

*Rebekkah Schear and Leigh Manasco, LIVESTRONG Foundation, Austin, TX, USA*

*Objective*

The goal of the project was to raise awareness among policy-makers, the public, health care providers and media about the challenges facing cancer patients in Japan. This would be achieved by strengthening patient advocacy through building the capacity of cancer NGOs to launch a grassroots campaign, empower patients to become engaged advocates and sustain a national call to action on cancer.

*Background*

LIVESTRONG Foundation and the American Cancer Society designed the Patient Empowerment Project to support a comprehensive, patient-informed national call to action on cancer through planning/implementing a cancer patient forum.

In 2009–2011, the programme was piloted successfully in South Africa and Mexico. In 2012, we launched the programme in Japan.

*Methods*

We selected the Health and Global Policy Institute as the local partner and collaboratively designed a strategy to build a network of key NGOs, recruit and engage patients, implement a national patient forum and grassroots campaign and launch/sustain a call to action. Technical assistance was provided on campaign development, implementation, monitoring and evaluation. We conducted three instructor-led trainings over 13 months to 20 NGOs and 30 patients about: identifying issues/developing an advocacy plan; grassroots advocacy; engaging media; and cancer storytelling/public speaking.

*Results*

Preliminary results indicated that:

- ▶ The adaptation and utilization of programme planning tools and grassroots advocacy methods have contributed to the successful launch of the Over Cancer Together campaign.
- ▶ Training cancer patients to share their stories publicly is an effective advocacy tactic in Japan which will increase the public and policy-makers' knowledge, awareness and value of patient experiences.

*Conclusions*

Cancer patients' voices are a powerful tool in advocating for improvements in attitudes, knowledge, practice, policy, systems and services.

*Implications*

Results confirm our prior conclusions that this model of patient empowerment results in identification and communication of patient needs and the necessary relationships and commitment between stakeholders to meet those needs.

*Abstract 3: Managers and administrators in health and insurance in cancer: Paradigms, learning and unlearning*

*Mariela Pow Sang, Luz Loo; Marga Lopez Contreras, Julio Abugattas and Doris Cardenas, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru*

Managers and administrators of public institutions play a decisive role in the management of insurance and cancer.

The need to strengthen the continuum of learning and unlearning with the insertion of new paradigms in the management of insurance makes the professional manager responsible for their own training in the areas of management and administration, public health and health care management, human talent management and contingency management. Additionally, the manager needs to understand the environment in which they operate and provide committed leadership.

This paper covered the need for training of managers and administrators in the areas of management and administration, economic and financial health management, payment mechanisms to suppliers, cost management, results-oriented management, better performance and strengthening the institutional accountability process, thus contributing to the process of management transparency.

Recent developments in Latin America set high standards for the performance of health managers and/or administrators - quality management with efficiency, safety, transparency, and with knowledge of priorities. Results of surveys establish the training needed for officers given the current context of insurance in cancer and health reform in the country.

*Summary of discussion by participants*

In summing up ways to promote and achieve better integration across regions and sectors, the four areas of focus comprise:

- ▶ Sharing and accessing information, knowledge and best

practice:

- implement policy with budget support;
  - public-private cross-sector workgroups;
  - establish and support volunteer programmes and training;
  - centralized accessible information;
  - ensure regional and geographic representation and inclusion;
  - share best practice training;
  - share progress through peer-reviewed publications and meetings.
- Providing opportunity for:
- allied health care professional training;
  - networking;
  - infrastructure and manpower support for NGOs;
  - help and training for information:
    - access;
    - understanding;
    - dissemination;
  - online and in-person learning;
  - attend professional and scientific conferences;
    - send appropriate representatives and managers (e.g., the people actually implementing the programmes).
- Prioritizing knowledge and information needs:
- establish national, regional and local guidelines and protocols;
  - support and maintain cancer registries;
  - conduct population-based surveys;
  - understand and analyse epidemiological and population-based data:
    - provide training.
- Being aware of and overcoming challenges and obstacles:
- non-interested and non-cooperative public agencies and policy-makers;

- bias towards servicing and supporting larger cities and metropolitan areas;
- capable management needed in all regions;
- unqualified personnel;
- lack of leadership;
- educational forums for patients must be accessible and affordable;
- bias towards high incidence cancers, rare cancers overlooked;
- lack of trained specialists.

### 3. Building a social movement

*Eva Maria Ruiz de Castilla Yabar, Esperantra, Peru and Alison Crepinsek, Campaign to Control Cancer, Toronto, ON, Canada*

Building a social movement for sustainable cancer prevention and control requires the right mix of skills and capacities employed in creative ways to engage a variety of stakeholders whose efforts in the aggregate lead to greater collaborative opportunities to address cancer. This workshop focused on three initiatives in Canada, Kenya and Brazil that seek to establish and add value to sustainable anti-cancer social movements.

In Ontario, Canada, the Engaging Emerging Leaders in Cancer Control (E2C2) targets students on the campuses of five universities throughout the province to become next-generation leaders of the cancer movement. In Kenya, the immense challenges related to cancer prevention and control are not easily separated from the volatile social, economic and political dynamics that are present in many African countries.

In Porto Alegre, Brazil, employees of the city’s main cancer hospital, Santa Casa de Misericordia, organize and participate each year in promoting healthy living by designing activities timed to coincide with the country’s national “fight against cancer” day.

*Abstract 1: Engaging Emerging Leaders in Cancer Control (E2C2): An innovative campus-based model for the next generation of cancer control*

*Alison M Crepinsek and Pat Kelly, The Campaign to Control Cancer, Toronto, ON, Canada*

Evidence is growing on the impact of youth engagement programmes in promoting resiliency and producing positive health outcomes by moderating or avoiding the onset of risk-taking behaviours (9, 10, 11). The years after age eighteen provide the context in which young people become increasingly independent from their parents, with post-

#### Box 2: Summary and recommendations from Workshop 2

- Create and sustain cross-sectoral region/sector/country opportunities for :
  - Leadership, training, person-to-person interactions, mentoring and workgroups
  - Stronger, organized and coordinated processes, plans, policies and accountability for national/regional/local improvement across regions including interactions and collaborations with NGOs and communities
  - Improved technology and use of virtual tools and interventions
  - Improve prevention infrastructure, e.g., “prevention trucks” with technology, trained professionals for preventive services and education
- It is imperative that interventions are prioritized based on evidence, experience and outcomes focus.

secondary institutions offering an ideal environment for influencing young adults during this transition period from home to independent living.

Focusing on the areas of health communication, social marketing and public health policy, Engaging Emerging Leaders in Cancer Control (E2C2) is a student engagement initiative, currently taking place at five post-secondary institutions in Ontario, Canada. It is a young adult-driven, participatory action approach where participants take part in knowledge transfer events with content experts from the Canadian Partnership Against Cancer and other cancer control institutions, to build understanding about cancer prevention, screening and early detection, and design evidence-based interventions for reducing long-term risk and sustaining successful behavioural change.

Student leaders were provided with benchmarking tools to assess the existing institutional and community environment regarding policies and practices that impact five priority areas for intervention:

- ▶ physical fitness and activity;
- ▶ healthy eating;
- ▶ tobacco use/exposure and alcohol misuse;
- ▶ UV exposure;
- ▶ HPV vaccination.

Students then engaged in priority-setting and campaign development promoting innovative action and leadership for cancer control.

The major finding and innovation emerging from this work is an overall approach to campus-based health promotion known as the healthy campus movement. Connecting to and championing the healthy campus movement, E2C2 has focused activities on promoting action for campus health promotion at both individual and systems levels. Our ongoing work positions university students as both ambassadors and change agents, with the meta-goals of building broad understandings of health into university organizational culture, and fostering critical health literacy amongst students, faculty and staff.

#### *Abstract 2: Cancer control in context of African socioeconomic and political upheavals*

*David M Kinyanjui, Aga Khan University Hospital, Nairobi, Kenya, and Lawrence I Gichini, Kenya Cancer Association, Nairobi, Kenya*

#### *Background*

Cancer control in a continent facing rapid social, economic and political changes presents unique challenges.

Priority cancer control policies are usually overlooked with every change of government. Economic and physical access to specialist health care for cancer patients is often compounded by cultural and political barriers including wars and conflicts. All this presents a major threat to sustained cancer control programmes across the continent.

#### *Methods*

A desk review, practice observations and interviews with key frontline cancer control advocates on the impact on their programmes of social, economic and political conflicts in Africa.

#### *Findings*

The cancer epidemic in Africa is happening in the context of wars, poverty and other social, economic and political challenges. National cancer control programmes, where they exist, can therefore not deliver effective services to address the growing problem which is expected to triple in the next 15 or so years.

#### *Conclusions*

Governments in Africa seeking to address the cancer problem may be facing the double tragedy of solving the problems of refugees and managing slum dwellers and internally displaced persons. These factors have a major influence on cancer control programmes and must be considered in programme design. Cancer control cannot be looked at from a biomedical perspective alone. It should be seen in the context of how the population interacts with the social, economic and political environment and how their right to health and liberty is respected. Innovative, culturally acceptable cancer control programmes can be delivered even with the challenges highlighted in this paper.

#### *Abstract 3: Flash Mob: Encouraging physical activity through dance for cancer prevention*

*Livia L Campo, Alice M Zelmanowicz and Dayane A Cicolella  
Irmandade Santa Casa de Misericórdia de Porto Alegre, Porto Alegre, RS, Brazil*

Cancer is a world health problem. The main risk factors are already known and many may be controlled. A healthy lifestyle and risk factor prevention can reduce the individual risk for the disease. An increasing number of studies show that more physically active individuals have a lower risk of cancer. Accordingly, education directed towards physically active lifestyles is appropriate. Every November, to coincide with the "National Day of the Fight

Against Cancer”, the Cancer Prevention Centre of Santa Casa de Misericordia de Porto Alegre (the cancer hospital) conducts activities to enhance health promotion. In 2012, individuals were encouraged to join activities that align awareness, promote pleasure and stimulate physical activity, including a “Flash Mob” – an instantaneous gathering of people in which dance is used to call the community’s attention to the importance of health promotion/physical activity.

For the campaign “Cancer – Live Healthily”, hospital employees were invited to advocate for lifestyle change through dance. The venue was a very busy city public park; the choreography was developed with a dance instructor; all participants rehearsed for three weeks and visual aids (t-shirts, banners and posters) were used. Fifty employees walked at random in the park and instantly gathered together to perform the dance.

The campaign motivated individuals to practice physical activities, with reported feedback indicating the satisfaction that dancing promotes and the demand for future events. Projects are being developed to provide the opportunity for more than 6,000 employees of the institution to participate in these activities and to stimulate population awareness of healthy habits and health-promoting behaviours.

#### *Summary of discussion by participants*

Post-workshop discussions focused on the need for the local community to recognize the value of design and implementation of creative programmes in order to engage stakeholders and social movements to advance sustainable cancer prevention and control. Workshop participants identified at least three strategies to help strengthen community-based programmes.

First, more educational programmes are required to address the stigma or social taboos surrounding cancer that continue to limit the ability of cancer control and prevention activities in many parts of the world. Second, more analysis and published case studies of what seems to work or not work well in building health-related social movements would allow for cancer practitioners and advocates to design, implement, adapt, and perfect programmatic interventions in their own communities. Third, civil society organizations that participate and many times lead such initiatives should find ways to work together more effectively so that the size and scale of cancer control and prevention activities at the community level become a movement to influence needed policy changes in the cancer arena.

#### Box 3: Summary and recommendations from Workshop 3

- Social movements can develop innovative activities to mobilize support for effective cancer control
- Civil society is necessary to formulate and implement cancer control policies
- Evidence-based initiatives in cancer control could help to develop innovative activities, e.g., pioneering activities embarked upon in cancer prevention by Engaging Emerging Leaders in Cancer Control (E2C2) in Canada

## 4. Strengthening organizational capacity and networking

*Margaret I Fitch, International Society of Nursing in Cancer Care, Canada, and Abel Limache-Garcia, Instituto Nacional de Enfermedades Neoplásicas (INEN), Peru*

Given the strong agreement that working together in networks or coalitions is desirable to make improvements in cancer control, the challenge is to understand how organizations and agencies can achieve effective levels of collaborative activity. Fundamental to gaining such understanding is learning from one another. Exploring what strategies have been effective in one setting can be useful in identifying what might be beneficial or adjusted for application in another setting. This workshop was designed to:

- Explore and understand organizational capacity and current limitations.
- Examine ways to go beyond the limitations to strengthen capacity, leverage opportunities, and create effective networks that can enhance advocacy activity aimed at improving the impact and patient benefit of cancer control.

Merriam-Webster’s online dictionary defines collaboration as “working with another person or group in order to achieve or do something”. Networks, coalitions and communities of practice are vehicles or ways of organizing for collaboration. They can include various numbers of partners or stakeholders and operate with various degrees of structure or operating requirements. Hallmarks of success include having a clearly defined goal, around which all can rally and exert effort, and strong leadership. Each of the stakeholders may contribute different skills and resources to achieve the shared goals. The collective effort drives the action toward achieving the desirable outcomes. To improve cancer control, collaboration is necessary at many levels (i.e., locally, regionally, nationally and

internationally).

The abstracts selected for this workshop provide illustration of strategies utilized by three different coalitions or networks. Each emphasized the need for growing awareness, sharing knowledge, sustained leadership, focusing on what is important to the community and using available technology.

*Abstract 1: Power of community collaborations: Change in access to services in coffee-growing communities involved in implementing cervical cancer prevention programmes*

*Rebecca M Singer, August Burns, Kayla Moore, Marin Brownell and Sarah Miles, Grounds for Health, Waterbury, VT, USA*

Grounds for Health (GFH), a US-based NGO, partners with coffee cooperatives and local health authorities to develop sustainable cervical cancer prevention programmes in coffee-producing countries. According to the World Health Organization, cervical cancer is the second most common cancer in women worldwide, with 85% of cases occurring in low-resource countries. GFH utilizes an innovative model that includes working with community health promoters (CHPs) affiliated with coffee cooperatives to address the barriers to access to preventive services at the community level. GFH also trains and supports local health care providers as they implement cervical cancer prevention services. Since 2007, GFH has collaborated with 14 different coffee cooperatives in Mexico, Nicaragua, Peru and Tanzania to mobilize communities for cervical cancer prevention.

Mobilization efforts have included training 428 CHPs to provide community education and recruit women at risk, as well as providing transport to services by cooperatives, resulting in 31,320 women gaining access to screening and treatment.

Since 2012, GFH has measured the impact of the collaboration on partner communities using the "Most Significant Change" process, a participatory qualitative methodology in which stories highlighting changes brought about by the intervention are collected from among those involved in the programme. Between April and September 2013, GFH staff conducted semi-structured interviews with cooperative members, community health promoters and health care providers in Peru and Nicaragua.

Through a process of review and selection involving a team composed of GFH in-country staff, local partners, and Vermont-based staff, stories were chosen that most comprehensively capture the impact of the programme on the community. Findings that highlight the changes experienced by the communities in which GFH collaborated

with local partners to implement cervical cancer prevention programme were presented.

*Abstract 2: Health Market*

*Sueli G Couto, Fabio S Gomes, Camila M Carvalho and Rebecca L Greenwood, Brazilian National Cancer Institute, Rio de Janeiro, RJ, Brazil*

The project "Health Market" is one of the actions developed by the Technical Unit of Food, Nutrition and Cancer Prevention, that is part of the Coordination of Prevention and Surveillance of the National Cancer Institute Jose Alencar Gomes da Silva and works from the perspective of health promotion. The project is based on knowledge dissemination and behavioural change related to healthy eating, physical activity and weight maintenance within the normal range, aimed at the prevention of cancer.

Scenographic foods of different groups are represented, including fruits, vegetables, salted meats, sausages, canned food, cereals and legumes, among others. Participants are invited to simulate a purchase. Then they are led to reflect on their food choices with nutritionists.

A wide adhesion and adaptation to the local context are both aspects that have facilitated its development in schools, public and private institutions and civil society organizations.

The integration of national, regional and local networks through the Brazilian Health System allows the proposal to have a wide diffusion, reaching even distant cities. It also makes the activity easy to reproduce, with the adaptation to regional foods. In a country like Brazil this is essential, given its huge geographical size and vast cultural diversity. The appropriation of the knowledge shared and the discussion of the determinants of food choices enables the development of critical attitudes in daily life. Participants became more sensitive to nutritional, cultural and economic aspects of foods.

*Summary of discussion by participants*

Workshop participants supported the importance of working through coalitions and networks to achieve the goals of cancer control advocacy. They described the critical importance of information and education in strengthening capacity and mobilizing action for change. However, they emphasized that this is not enough. Other strategies are necessary to overcome the limitations in knowledge, resources, policies, leadership, attitudes and access to intended audiences.

Working locally within and through the communities and phasing implementation is critically important. Identifying

existing groups and local leaders should be an early step. These leaders can be engaged actively in identifying the issues as the community perceives them and specifying culturally appropriate approaches for any advocacy action or activity. Education and training of these local leaders is most important if they are to be champions for change or knowledge brokers and help to gain the engagement of the broader community. Listening to the community and understanding what is important to them and their view of specific issues is vitally important. Success will be realized more easily if the community perceives the advocacy work is on an issue they see as important and is being conducted in a culturally relevant manner through credible individuals (or organizations).

Implementation requires a clear message and multiple channels to communicate that message. The message should be clear and simple but also compelling. It ought to be the same message for all but take different formats for different audiences. The emergence of various social media provides many opportunities to connect and communicate with various audiences. Training may be necessary in skills such as communicating, marketing and presenting.

Strengthening capacity and mobilizing action may require working across traditional boundaries. Multidisciplinary, interprofessional and intersectoral groups may be required, depending on a specific issue. Effective advocacy needs to draw on the expertise of many, with a strong grassroots base and clearly identified leadership to direct the activity. Designing a master plan can be a tremendous help in guiding actions. The plan must outline priorities, what actions will be taken, and who is responsible for each. Both short-term and long-term objectives need to be articulated as actions will likely need to be phased over time.

#### Box 4: Summary and recommendations from Workshop 4

- Training of local providers is key
- Work closely with local leaders within existing local networks on matters important to the community
- Identify (and work through) cultural brokers to ensure culturally appropriate approaches

## Discussion and conclusion

*Cristina Parsons Perez, Catalyst Consulting Group, London, UK, and Eva Maria Ruiz de Castilla Yabar, Esperantra, Peru*

In the Latin America and Caribbean region, the last five years have seen increased efforts in advocacy with patient organizations at the forefront of raising public demand and voicing the need for improved policies in cancer control. One

trend commonly observed is the regional and national emergence of advocacy coalitions. Networks are seen as an essential part of advocacy, offering a way to pool resources, expertise and connections and, importantly, offering a powerful and united cancer civil society front in influencing policy-making. Advocacy coalitions are organized around clearly established advocacy goals and, under the leadership of strong patient organizations, offer a low risk way of smaller patient organizations less versed in advocacy to get involved and contribute towards change. Another trend observed in the region is that of utilizing social media as an innovative way of mobilizing grassroots, moulding public opinion and getting an advocacy message across. From examples in Argentina of using real time social media to denounce the lack of cancer medications, to examples in Mexico of using a Twitter campaign targeting the Ministry of Health, to the Caribbean Cervical Cancer E-Petition and ULACCAM’s online declaration of rights using the Avaaz platform, the region is demonstrating growing e-advocacy skills, using technology as well as truly unlocking the power of grassroots. Increasingly innovative approaches to engaging grassroots are being used in the region, with models available for engaging the university student community as well as interesting examples being explored on promoting healthy behaviours in the general public. Just as increased advocacy capacity is seen strongly emerging from civil society, government representatives are simultaneously realizing the power of engaging patient organizations as these can mobilize public opinion and help create the groundswell demand for changes and investments, enabling the government to improve cancer control.

There is overall agreement that effective cancer control requires local leadership and that the strengthening of local leadership and provider capacity is important to ensure implementation of strategies in a culturally appropriate manner. Capacity-building is thus an essential part of creating and sustaining cross-region/sector/country collaboration. Coordinated processes, plans, and policies with robust accountability mechanisms for national/regional/local implementation that include interactions and collaborations with NGOs and communities will be one important piece in ensuring the engagement of “all of society”.

This session raised multiple elements for consideration, including how to better impact public policy while informing and engaging “all of society”, how the capacity of civil society organizations, key advocates and networks are critical for success, and how effective communication – both internally among stakeholder groups and externally to communities

and the public at large – is the foundation for building sustainable cancer movements.

Members of the cancer community are urged to look internally at how they might work more effectively in multisectoral coalitions and networks, harnessing technology to provide continuous opportunities to learn how to be more effective both as individual leaders and collaborators in the cancer movement. Advocates are encouraged to focus their external efforts on health system integration, on engagement at the community level that is relevant for the given cultural context, and on building a steadily progressive political conscience about cancer at all levels of society. The use of evidence to inform, guide and inspire cancer advocacy efforts is paramount, now more than ever, as is the ability of advocates to clearly define for health authorities the value of engaging civil society organizations. The success of population-based cancer control activities will depend highly on the level of involvement of cancer advocates in policy design and decision-making processes, as well as programme implementation and evaluation.

This session concluded that a unified “all of society” cancer control agenda is bigger than any one player or sector. Effective cancer control will require working across traditional

boundaries with multidisciplinary, interprofessional and intersectoral approaches. The deliberations laid emphasis on how essential it is that civil society be mobilized with a clear vision and mission for cancer control purposes; the importance of the involvement of advocates in cancer control discussions and decision-making; the crucial role of advocates as watchdogs of the political system; the championing of evidence-based advocacy and evidence-inspired advocacy; and finally, the all important first step – the creation and promotion of a political conscience in society.

#### Acknowledgments

*This manuscript is a synthesis of plenary presentations, workshop discussions, including selected abstract presentations, and recommendations for ongoing actions derived from Session 2 of the Fifth International Cancer Control Congress (ICCC-5) held in Lima, Peru, 3–6 November 2013. The ICCC-5 working group was made up of Simon B Sutcliffe, Kavita Sarwal and Catherine G Sutcliffe from the International Cancer Control Association, Tatiana Vidaurre Rojas and Roxana Regalado from the National Cancer Institute (INEN) in Peru. The opinions expressed herein represent those of the authors alone and do not necessarily represent the institutions and organizations by which they are employed.*

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# THE FIFTH INTERNATIONAL CANCER CONTROL CONGRESS

## SESSION 3: IMPROVING POPULATION HEALTH: USING DATA AND EVIDENCE TO SUPPORT POLICY AND PROGRAMMES

# SESSION 3: IMPROVING POPULATION HEALTH: USING DATA AND EVIDENCE TO SUPPORT POLICY AND PROGRAMMES

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The prevention of cancer and the implementation of programmes to bring this about can only move forward in the clear light of an evidence-based framework. Unfortunately, in many low- and middle-income countries basic statistics, such as the burden and site distribution of cancer, the prevalence of major risk factors and the health gain introduced by prevention policies are complete unknowns. Thus, early in the planning of cancer control, data acquisition and accumulation of evidence relevant to different stakeholders is essential. Session 3 of the Fifth International Cancer Control Congress (ICCC-5) focused on how to improve the health of the population through risk factor control and early detection activities with a focus on using data from registries and surveillance. There were three plenary presentations and four interactive workshops covering the following topics:

- ▶ Policies around screening and early detection programmes in low- and middle-income countries.
- ▶ Communicating the evidence: The role of the health care provider and community health promoter in informing health-seeking behaviour.
- ▶ Surveillance and disease monitoring and the barriers to implementing effective cancer registration.
- ▶ Surveillance of risk factors: Understanding cancer-related exposures to impact research and prevention activities.

Workshop discussions highlighted the diversity in screening tests and technologies used around the world and the lack of current recommendations and evidence to inform policy; the disconnect between those generating and implementing guidelines and policies and the need for training of both providers and promoters of population health; the need for better registries in low- and middle-income countries that have standardized procedures, appropriate electronic technologies and software, and short-, mid- and long-term plans to ensure sustainability; and the need for standardized national health surveys to collect information on exposures to risk factors.

*Key words: cancer control, registries, surveillance, screening and early detection, health communication*

## Introduction

*David Forman, International Agency for Research on Cancer (IARC), Lyon, France, and Carlos Santos, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru*

The use of data and evidence in support of cancer control would appear, at first sight, not to require any justification. Indeed one would anticipate that data collection to develop informed evidence-based cancer control policies would rank as one of the highest priorities for all those involved in formulating policy in the public health field. However, it is unfortunately the case that in many areas of activity, cancer control workers are operating in an evidence-free black hole. This is particularly the situation in many low- and middle-income countries (LMICs) where such basic statistics as the burden and site distribution of cancer, the prevalence of major risk factors and the health gain introduced by prevention policies are complete unknowns. Thus, in starting out on the pathway of cancer control, it is necessary at an early stage to gather data and accumulate evidence.

Evidence can take many shapes and forms and different components are of relevance to different sectors of the community. Evidence is needed for the general public as much as for the health professional, and the presentation of information, however well researched, for one audience may not be of benefit for another. Different messages and different styles of messaging are required for the lifelong smoker seeking information on how to quit and for the public health doctor trying to create smoke-free environments. Both need to know about the impact of tobacco in their populations, the range of cancers caused by smoking and the benefits of cessation; but how this should be packaged and delivered will be fundamentally different in the two situations.

This session sought to take a broad perspective on data and evidence in the cancer control arena, considering different types of relevant evidence, different modes of delivery and different groups making use of the end product. Plenary presentations provided:

- ▶ An overview of the understanding brought about by data collected by population-based cancer registries and approaches to the building of capacity in cancer registration especially in populations where it is absent or of poor quality (Forman).
- ▶ A summary of the new WHO guidelines on cervical cancer prevention (1) including all the available modalities for early detection of this disease, its subsequent management, and the assessment of the relative benefits of different approaches (Broutet).

- ▶ How evidence-based approaches to cervical cancer prevention have been employed in Peru, realizing the “translations” of screening and early detection methods into realizable procedures for use in field conditions and the evaluation of the strategy in terms of cancers avoided (Santos).

Two of the four subsequent workshops picked up the themes covered in the plenary presentations. Consideration was given to the development of screening and early detection programmes and the barriers facing those seeking to establish cancer registries in LMICs. The other two workshops provided different elements:

- ▶ how to communicate evidence and the role of health professionals in promoting health-seeking behaviour; and
- ▶ the process of risk factor surveillance to build up a picture of cancer-related exposures in a population as a means of informing research and prevention.

The collection of data and the compilation of evidence are often seen as the exclusive terrain of research. In many respects this is correct, as research methods provide instruction on how to conduct these activities. However, the end result of these processes is not confined to peer reviewed research papers (important though these are). Without hard data and clear evidence, policy development for cancer control, at best, cannot get started and, at worst, can go in the wrong direction. The prevention of cancer and the implementation of programmes to bring this about can only move forward in the clear light of an evidence-based framework.

## Methodology and objectives

ICCC-5 Session 3 on “Improving population health: Using data and evidence to support policy and programmes” comprised three plenary presentations to provide an overview of the subject matter as a means of preparing Congress participants for participating in four, small group, interactive workshops on relevant topics to be addressed in greater depth. Selected abstracts providing particular insights into the topic area were presented orally by the authors in each of the workshops. Workshop leaders were encouraged to conclude their workshops with a brief set of prioritized recommendations to identify the key directions for further development of interventional activities beyond this Congress.

The objective of this session was to explore how to improve the health of the population through risk factor control and

early detection activities with a focus on using data from registries and surveillance. The following four issues were selected for in-depth discussion in the workshops:

- ▶ Policies around screening and early detection programmes in LMICs.
- ▶ Communicating the evidence: The role of the health care provider and community health promoter in informing health-seeking behaviour.
- ▶ Surveillance and disease monitoring and the barriers to implementing effective cancer registration.
- ▶ Surveillance of risk factors: Understanding cancer-related exposures to impact research and prevention activities.

## Plenary presentations

### 1. Registries, data and measurement

*David Forman, International Agency for Research on Cancer (IARC), Lyon, France*

Last year saw the publication of the tenth volume of *Cancer Incidence in Five Continents (CI5) (2)*, the serial publication produced by the International Agency for Research on Cancer (IARC) that provides a synthesis of information about the incidence of cancer around the world from high quality population-based cancer registries. Comparisons of data from this volume (with cancers diagnosed around 2005) with those from the first volume (cancers diagnosed around 1960) shows the substantial increase in the burden of cancer in nearly all populations. However, the new data also show the enormous variation between populations in the current incidence of all major cancers – thus lung cancer in men shows a 20-fold difference comparing high rates in Izmir, Turkey or Kentucky, USA (the home of tobacco), with low rates in Cuenca, Ecuador or Ambillikai, India. Cervical cancer shows a 40-fold variation despite declining rates in many high risk populations, while breast cancer and malignant melanoma both show an approximate 10-fold variation between high and low risk populations.

This type of very basic information (and there are many more examples) allows one to direct cancer control priorities for a specific population by providing an answer to questions about the magnitude of the cancer burden, the potential for change, emerging concerns and the impact of policy. Other outputs from cancer registries can monitor the impact of early detection policies (by monitoring stage at diagnosis), the effects of treatment (by survival analysis), the resource requirements for treatment and support (through prevalence estimates) and future projections of the overall burden.

The number of registries contributing to CI5 has grown

considerably, from 31 to 290, over the ten published volumes yet, even now, a much higher proportion of the population from high-income regions is represented (e.g., 95% of North America) compared with Africa (1.9%), Asia (5.7%) or South America (7.5%). In response to this inequity in cancer surveillance, IARC has, in partnership with many other international organizations, established a new Global Initiative for Cancer Registry Development (GICR) with the aim of improving capacity in LMICs to produce reliable high-quality information on the burden of cancer (3). This is timely, given the recent UN Political Declaration on Non-Communicable Diseases (4) and the related WHO NCD Global Monitoring Framework (5) with the requirement for each country to report its cancer incidence and site distribution. GICR aims to support capacity-building through advocacy, training, support, networking and research for registries delivered through regionalized resource centres or “hubs”, now established in Africa, Asia and Latin America.

### 2. Revised WHO guidelines for a comprehensive approach to cervical cancer prevention

*Nathalie Broutet, World Health Organization, Geneva, Switzerland*

Cervical intraepithelial neoplasia (CIN) is a premalignant lesion that may exist at any one of three stages: CIN1, CIN2 or CIN3. If left untreated, CIN2 or CIN3 (collectively referred to as CIN2+) can progress to cervical cancer. Instead of screening and diagnosis by the standard sequence of cytology, colposcopy, biopsy and histological confirmation of CIN, an alternative method is to use a “screen-and-treat” approach in which the treatment decision is based on a screening test and treatment is provided soon or, ideally, immediately after a positive screening test. Available screening tests include an HPV test, visual inspection with acetic acid (VIA), and cytology (Pap test). Available treatments include cryotherapy, large loop excision of the transformation zone (LEEP/LLETZ) and cold knife conization (CKC).

WHO developed recommendations on strategies for a screen-and-treat programme (1, 6). It builds upon the existing recommendations for the use of cryotherapy to treat CIN (7) and on the new recommendations for the treatment of CIN2+ (8). The guideline is intended primarily for policy-makers, managers, programme officers, and other professionals in the health sector who are responsible for choosing strategies for cervical cancer prevention, at country, regional and district levels. For countries where a cervical cancer prevention and control programme already

exists, these recommendations were developed to assist decision-makers in determining whether to provide one screening test followed by a treatment or to provide a series of tests followed by an adequate treatment. For countries where such a programme does not currently exist, these recommendations can be used to determine which screening test and treatment to provide. In addition, a decision-making process flowchart was developed to help programme managers choose the right strategy given the specific country or regional context.

The methods used to develop these guidelines follow the *WHO Handbook for Guideline Development* (9). A Guideline Development Group was established that included experts, clinicians, researchers in cervical cancer prevention and treatment, health programme directors and methodologists. An independent group of scientists at a WHO collaborating centre conducted systematic reviews on the diagnostic accuracy of the available screening tests and the effects of different treatments for CIN. This evidence was used to model and compare different screen-and-treat strategies in women of unknown HIV status and HIV-infected and uninfected women and the results were presented to the Guideline Development Group in evidence tables following the GRADE (Grading of Recommendations, Assessment, Development and Evaluation) approach (10).

Although the best evidence to assess the effects of a screen-and-treat strategy is from randomized controlled trials, we identified few randomized controlled trials that evaluated these strategies and reported on important patient outcomes. Areas for future research include screen-and-treat strategies using a sequence of tests (e.g., HPV test followed by VIA); screen-and-treat strategies in HIV-infected women; and measurement of important health outcomes following a screen-and-treat strategy.

### 3. Building capacities in the control of cancer in women in Peru

*Carlos Santos, Instituto de Enfermedades Neoplásicas (INEN), Lima, Peru*

Uterine cervix cancer is a public health problem in Peru. Previous secondary prevention efforts have failed mainly due to lack of coverage and lack of management of positive cases. To adequately face and solve this situation it is necessary to evaluate local applicability of current common screening methods, consider alternatives to be prioritized according to prevalent conditions in different settings (mapping), and contemplate task shifting represented by empowering medical and non-medical health personnel

regarding new primary screening methodologies and adequate management of positives.

#### *Evidence about cervical cancer screening interventions*

Cytology-based programmes have been successful in decreasing cervical cancer incidence and mortality in many high-income countries (HICs). This has not been replicated in LMICs due to problems inherent in the primary screening method (cytology) and also organizational aspects interfering with adequate coverage and management of positive cases. Worldwide, cytologic sensitivity for high grade pre-invasive disease is far from satisfactory at around 55%. Moreover, coverage is not synonymous with success in many LMICs, mainly due to inadequate follow-up and treatment of positives.

Alternative screening methods, both high and low technology, should be considered. High technology methods are best represented by HPV tests and molecular biomarkers. Although HPV tests, looking mainly for DNA, are the most sensitive for CIN2+, they are demanding in terms of cost and the need for molecular biologists. The “careHPV test”, said to be a reliable, fast and affordable method, is not yet widely available. Consequently, low technology approaches are best suited for low-resource settings.

In this context, visual inspection with acetic acid (VIA) is an appealing approach, especially when used in conjunction with cryotherapy under the concept of “see-and-treat”. VIA has been demonstrated to surpass cytology in terms of sensitivity. Although less specific, it is a practical method whose main virtue is an immediate result which permits immediate treatment if necessary.

#### *Prioritizing interventions according to local conditions: Alternative methodologies*

There have been some cytology-based cervical cancer secondary prevention efforts in Peru in the past, but they have been uniformly unsuccessful. Considering the low sensitivity and relative complexity of a programme based on cytology, settings with inadequate organizational and economic conditions that need to expand prevention programmes in the near future must focus on alternative approaches. Although the future of cervical cancer screening is molecular, for practical reasons we consider the “see-and-treat” approach using VIA and cryotherapy to be the best choice for the majority of Peruvian regions. This has been supported by many experiences, including a programme in India that succeeded in reducing cervical cancer mortality by at least 30% (11). Creation of a VIA-based system will require

extensive training of human resources.

#### *Reaching health care providers and community health promoters*

**Building capacity:** Under these principles, a Training Excellence Center for Cervical Cancer Management was created at the Gynecologic Oncology Department of the Peruvian Cancer Institute (INEN) in 2006 with a focus on VIA-based secondary prevention. With collaboration from IARC, the Program for Appropriate Technology in Health (PATH) and the Johns Hopkins Program for International Education in Gynecology and Obstetrics (JHPIEGO), a complete educational package was developed, tested and validated in order to create a pyramidal care system with promoters, VIA-CRYO screening and treatment providers, and colposcopists on the next level. In parallel, educational teams were trained to sustain the “cascade effect” in every region, empowering them to have their own training capabilities to respond to particular demands in the future. So, promotion trainers, clinical trainers and master trainers were formed.

#### *Value of training excellence centres*

In addition to promotional and clinical activities, the training covered implementation and supervision of prevention programmes. Six trainer teams were formed all over the country. Nationwide training was initiated when the national prevention programme was launched in August 2012. Currently, 946 providers, 37 trainers and six master trainers have been trained in the country. Additionally 285 promoters and 93 trainers in promotion have been formed.

The programme has been replicated in Colombia, Nicaragua and Bolivia, with a total of 217 providers, 28 trainers and eight master trainers in Colombia and Nicaragua. Taking into consideration the challenges posed by increasing the demand of services, a virtual web-tool will be developed in the near future to support training and supervision activities.

## **Workshops**

### **1. Policies around screening and early detection programmes in low- and middle-income countries**

*Edward J Trapido, Department of Epidemiology, Louisiana State University School of Public Health, New Orleans, USA, and Jose Jeronimo, PATH, Seattle, USA*

In an ideal world, all cancers would have screening tests that could detect precancerous lesions, and effective treatment could be given to cases diagnosed through screening, improving the survival and quality of life of people. The test would have high sensitivity and high specificity, and would be reliably high in its predictive value. Screening programmes

would be systematic rather than sporadic. The tests would be inexpensive, widely available and acceptable to asymptomatic individuals.

For many years, at least for HICs, there had been general agreement about which cancer screening modalities were recommended, the ages at which they should be applied, and the effectiveness of treatment of these cancers. For countries with fewer resources, their goals were frequently to emulate wealthier nations, whether or not the capital and human resources existed locally. Accordingly, most still have no screening programmes, or if available, the coverage and quality are very limited resulting in little impact on the burden of disease.

Perhaps beginning with the overuse of Prostate Specific Antigen (PSA) for prostate cancer screening, the research and practice community began to re-examine the evidence upon which cancer screening modalities were used and recommended. PSA testing resulted in an excessive number of false positive results, identifying individuals whose tumours would not become lethal during their lifetimes. Such individuals were faced with options which might leave them incontinent or impotent.

Following PSA, there was a growing controversy over mammography, breast self-examination, and clinical breast examination. Were guidelines for their usage really evidenced-based? For cervical cancer, new options also appeared, focusing more on the cause (HPV infection) than on the early disease manifestations (carcinoma in situ of the cervix). For lung cancer, use of spiral computed tomography (CT) was becoming overly common before there was evidence that it might be useful.

Besides the scientific reassessments, countries with low economic resources cannot afford the more technologically driven techniques, nor do they have sufficiently trained individuals to follow up and treat screen-detected cases. Thus, there has been a need to identify less costly, more acceptable, and more scientifically-based approaches to cancer screening.

The purpose of this workshop was to examine the current evidence for cancer screening modalities and to illustrate successful programmes used in both HICs and LMICs. Participants were asked to talk about what was available and used in their countries, and how decisions were made, and who by, about cancer screening.

#### *Abstract 1: What does science tell us about current screening recommendations?*

*Edward J Trapido, Department of Epidemiology, Louisiana State University School of Public Health, New Orleans, USA*

The evidence for long-practiced screening recommendations using mammography, clinical and self-examination of the breast; Pap smears; colonoscopy, digital rectal exam, fecal occult blood testing and sigmoidoscopy, and PSA testing is either waning or has changed. Population-based mammography has not slowed the rate of diagnosis of late stage breast cancer, which is where most mortality occurs. Clinical breast exam has not been thoroughly tested in multiple settings in the absence of mammography and breast self-examination has not been proven to be effective. Pap smear testing is useful, if and only if it can be followed by rapid reading and treatment. Instead, HPV testing followed by cryotherapy is often preferred, especially in LMIC locations. Fecal occult blood testing, sigmoidoscopy, digital rectal exams, and colonoscopy may be only marginally effective and guidelines for colonoscopy frequency after age 50 are in flux. PSA testing is no longer recommended, producing far too many false positive tests leading to unnecessary worry and often damaging treatment. For lung cancer, low-dose screening using low-dose helical computed tomography (CT) has shown a 20% reduction in deaths among current or former heavy smokers compared to chest X-ray, but population-wide screening is unnecessarily costly. In fact, because screening often results in overdiagnosis of disease which would never have been lethal, survival time post-diagnosis is not direct evidence of a benefit from early detection. Similarly, if a larger proportion of patients with screen-detected cancers are alive at five years, this might be an effect of lead time bias or screening picking up cases which were slower growing and less aggressive tumours (i.e., due to length-biased sampling). Critical review of the current recommendations and limitations of screening modalities set the stage for a discussion of policy options in Latin America.

*Abstract 2: Changing paradigms in cervical cancer prevention: The need for using self-collected vaginal samples*

*Jose Jeronimo, PATH, Seattle, WA, USA*

*Objectives*

Cervical cancer is still one of the leading causes of cancer-related mortality in women in developing countries. There are millions of women in need of screening and one of the limitations of the current screening tests is the need for pelvic evaluation. PATH conducted a demonstration project to compare the feasibility of using self-collected vaginal samples for HPV testing with other screening options, since that strategy could increase the coverage of screening in low-resource settings.

*Methods*

Approximately 20,000 women were enrolled in India, Uganda and Nicaragua. After informed consent, participants were instructed to self-collect a vaginal sample for careHPV™ testing; then a health worker performed a pelvic evaluation and collected cervical samples for careHPV™ and cytology, followed by visual inspection with acetic acid (VIA). Participants with any positive screening test had colposcopy and biopsy. Cases are defined as any woman with a histological diagnosis of CIN2+.

*Results*

Overall, more than 90% of women agreed to self-collect a vaginal sample, the lowest being in Nicaragua (81.1%), followed by Hyderabad, India (90.7%) and the highest in Uttar Pradesh, India, and Uganda (99%). The sensitivity of the self-collected vaginal sample for detecting CIN2+ cases was higher than the sensitivities of Pap smear or VIA in all sites.

*Conclusions*

Self-collection of vaginal samples was highly accepted in Nicaragua, India and Uganda. The sensitivity of careHPV™ using self-collected samples was superior to other tests that require pelvic examination. HPV testing using self-collected samples appears to be the best option for expanding coverage of screening for cervical cancer in areas with limited resources and where millions of women between 30–49 years are in need of screening.

*Abstract 3: Comprehensive approach to shifting from Pap to HPV-based screening: Results from the Argentinean Demonstration Project*

*Silvina Arrossi, CONICET/CEDES, Buenos Aires, Argentina and Instituto Nacional del Cáncer, Buenos Aires, Argentina; Laura Thouyaret, Instituto Nacional del Cáncer, Buenos Aires, Argentina; and Rosa Laudi, Ministerio de Salud, Buenos Aires, Argentina*

In 2011, Argentina launched a Demonstration Project to introduce HPV testing as a primary screening tool in the Province of Jujuy, one of the provinces with the highest cervical cancer mortality rates. The project involved introducing HPV testing in the public health system for women aged 30 and over, and triage with cytology for HPV+ women.

The project was led by the National Cancer Institute in collaboration with the National Program of Cervical Cancer Prevention. During 2011, key activities were planned and implemented through a consensus process that involved main stakeholders and decision-makers. The screening

phase began in 2012 and is planned to take place during 2012–2014. The goal is to screen 22,000 women annually over three years, to reach 80% coverage.

Consensus to introduce HPV testing was agreed with scientific societies, representatives from provincial ministries of health, and key opinion leaders. A HPV laboratory was organized at Jujuy's main hospital as part of the Pathology Service. At present all 300 provincial health care centres are offering HPV testing to women aged 30 and over. During 2012, 23,175 women were screened for HPV in the public health care system; 2.8% of them were younger than 30. Among the 22,589 women aged 30 and over who were screened, 12.7% tested HPV+, of whom 921 had an abnormal Pap smear. By 31 May 2013, 51% of HPV+ women with an abnormal Pap had colposcopies and biopsies if needed. Based on these preliminary results, detection rate of histologically confirmed CIN2+ was 1.04% (239/22,589).

Introduction of HPV testing in Argentina was successfully

implemented and based on these results, the Ministry of Health is expanding the strategy to all 24 provinces. This project demonstrates that HPV testing can be introduced at a programmatic level in middle-low income countries.

## 2. Communicating the evidence: The role of the health care provider and community health promoter in informing health-seeking behaviour

*August Burns, Grounds for Health, Waterbury, USA, and Abel Limache-Garcia, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru*

A well-informed population translates into a healthier population. While data about best practice informs policy, this information is often not passed on to health care workers, community health promoters or those seeking health services in a language they understand so as to inform practice and health-seeking behaviour. Without up-to-date, correct and easily understood information, the individual is at risk of being lost in a cycle of ill health and less than optimal care. To be informed, patients must understand the risks and benefits of their health options, whether for prevention or treatment, but health literacy is not solely the responsibility of the individual patient or consumer, it is also the responsibility of health communicators to choose carefully how to present health information. When that information is shared effectively, it will motivate the target audience to choose health-seeking behaviours.

Communication is not simply word choices or clear messaging. Barriers to the movement of health information in low-resource settings include lack of research results available in local languages, poor communications infrastructure such as internet access, need to translate messages into multiple languages, cross-cultural appropriateness, difficulty in assessing feasibility of introducing new practices in lower-resource settings, lack of print materials and challenges in keeping existing materials up-to-date, as well as little to no focus on effective communication training for health communicators.

An important resource for improving communication is the well-trained Community Health Promoter (CHP). Once policy has been put into practice, the CHP is in the unique position of having access to the target population, and when his/her outreach is coordinated with health care providers, under-served populations can gain access to much-needed health information to help inform their decisions and dispel myths and misinformation. CHPs can also play a key role in reducing the problem of loss to follow-up.

The workshop explored how to communicate information

### Box 1: Summary of Workshop 1

#### Cervical cancer

- Every country routinely uses different sets of screening tests
- Even within a country different screening tests are being offered
- There is considerable controversy in countries about whether to stay with Pap smears or move to VIA and cryotherapy

#### Breast cancer

- The recommended age and testing interval for mammography varies by country
- Current evidence is insufficient to determine the benefits and harms of CBE
- Some countries are still recommending breast self-examination

#### Prostate cancer

- Many countries are still doing PSA screening

#### Lung cancer

- One country in Latin America is about to start screening for lung cancer among heavy smokers using low-dose CT

#### Stomach cancer

- Stomach cancer is of particular concern for Peru, a country with a moderately high incidence rate
- There are limited possibilities for early detection; more work is required

#### Colon cancer

- Colonoscopy is being done in some countries but only one is moving to the new fecal immunochemical test (FIT)

about best practices and new policies to health care providers working directly with patients, how to translate this information into language that communities will understand, and the role of the CHP in community engagement, education and behaviour change. In addition, strategies to facilitate, empower, and fully engage the CHP in cancer prevention activities were discussed as a critical factor for success. These issues were explored through discussions of case studies to identify the elements needed to implement successful programmes; the cultural, economic and social factors that impact programme implementation; and the elements of programmes that have succeeded in changing health-seeking behaviour as related to cancer prevention, diagnosis and treatment.

**Abstract 1: CASTLE: Creating access to screening and training in the living environment**

*Faye C Parascandolo and Angela Frisina, McMaster University School of Nursing, Hamilton, ON, Canada*

CASTLE is a strengths-based project built on partnerships and peer support that focuses on increasing the rates of screening for breast, cervical and colorectal cancers in under- or never-screened communities of six regions in central Canada. Research evidence indicates that residents of lower socioeconomic status are more likely to be under- or never-screened for breast, cervical and colorectal cancers. Income, employment, education and literacy, culture, physical and social environments, health practices and access to health services are well known determinants that influence overall health and cancer screening specifically. All project sites met the project inclusion criteria of low income, low cancer screening rates and relevant community assets.

CASTLE's goal is to engage, empower and educate these communities regarding cancer screening and encourage participation in three organized cancer screening programmes. Several innovative engagement strategies that have the potential to be replicated across Canada and other regions are being utilized. Using a strengths-based community engagement model, the project employs local peer educators, called Community Health Brokers (CHBs), from each community. CHBs engage vulnerable communities through education, event participation, local advertising and social media. Based on community needs and assets, they facilitate residents in overcoming barriers to cancer screening and addressing health service access issues.

Positive results are emerging to suggest CHB interventions are effective in reaching these communities. Data are captured through journals written by CHBs and their

mentors. Main themes in the CHB role include relationship building and community engagement. The importance of establishing trust is an overarching theme and is essential to the project's success. Unique stories from each of the communities demonstrate the lessons learned regarding individual and societal factors as well as facilitators and barriers to cancer screening. Plans to sustain the project and transfer to other regions are being developed.

**Abstract 2: Factors affecting attendance at cervical cancer screening among women in the Paracentral Region of El Salvador**

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**Objective**

To identify factors affecting women's participation in a public sector HPV-DNA-based cervical cancer screening programme in rural El Salvador.

**Methods**

Women aged 30–49 years were chosen randomly among participants who attended an educational talk about the opportunity to receive HPV-DNA-based screening with the novel test, careHPV™ (Qiagen, Gaithersburg, MD, USA). Prior to the talk, informed consent was obtained and the survey was administered, which included questions regarding sociodemographic factors, access to health services, previous screenings and knowledge about HPV. Immediately following the educational session, women were scheduled a screening appointment at a local clinic within two weeks. Subjects were considered adherent if they attended their scheduled appointment or rescheduled and attended an appointment within six months.

**Results**

A total of 409 women were enrolled in the study, of which

22.8% had not received screening within the previous three years and were considered under-screened. All women received a scheduled appointment, of which 88% attended. Of the 12% who did not attend, the only factors associated with non-adherence were a greater number of sexual partners (4+) and more than three years since the last screening ( $p < 0.05$ ). Factors such as number of children, distance to the health clinic, and available transportation were not associated with adherence.

#### Conclusions

The educational talk was an effective method for recruiting and scheduling HPV screening appointments; however, because a random selection of women were invited to participate and the overall screening rate for Salvadoran women is considered to be less 20%, we expected a greater number of attendees to have a history of non-screening. Overall, compliance with screening was high, yet women with a history of non-screening were less likely to attend. Further studies are needed to identify both the factors associated with non-adherence, and effective recruitment methods targeted at this at-risk population.

#### Abstract 3: A professional education programme on cervical cancer prevention: Results of an e-learning experience

Francisco J Bosch, José M Borrás, Patricia Pérez, Assumpta Company, Ana Sedano and Mireia Montserrat, Institut Català d'Oncologia (ICO), L'Hospitalet de Llobregat, Barcelona, Spain

#### Background

Cervical cancer remains the second most important cancer in women worldwide and the cancer priority in most developing countries. It is largely preventable and if diagnosed and treated at an early stage is highly curable. In the absence of efficient preventive action, it is usually diagnosed in advanced stages and is a major cause of death among young women. The advent of HPV vaccines and the impact of screening represent a milestone opportunity for prevention. The introduction of a new vaccine targeting women worldwide requires that literally tens of thousands of health professionals and decision-makers understand its value and mode of use. A virtual course has been designed to provide such information to health professionals worldwide without costs to the participant.

#### Objectives

1. Create and promote an e-learning educational programme on HPV and cervical cancer epidemiology and prevention suitable for a wide audience of health professionals.

2. Create an international network of professionals qualified as key trainers in cervical cancer prevention in critical countries.

#### Results

The project was supported by various unrestricted educational grants. The technological platform and the scientific and pedagogical methodology were provided by e-oncología, the e-learning platform from Catalan Institute of Oncology (ICO), Barcelona, Spain.

Output was an 18-hour long distance course in Spanish, English, French and Russian. The contents are largely based on the ICO HPV Monograph series. The programme was scientifically validated and endorsed by FIGO, UICC, IAEA, IARC and WHO, and is freely distributed. Since 2011 more than 8,000 professionals worldwide have registered for the course, a pool of 32 international tutors have been certified and acted as course professors in their own environment, and 70% of the students have been certified.

#### Conclusion

E-learning methodology with a tutorial support can be a good and affordable solution to the medical education in low-income countries and the contents are easily adapted to each country.

#### Box 2: Summary of Workshop 2

- Training of health care providers appears to be working well in the countries represented
- Many modalities are being used that are adapted to reach the target audiences
  - for example, working with community leaders, established community groups/ programmes and sports events
- Training of trainers should be implemented for both professionals and community health promoters
- There is a disconnect between those generating and implementing protocols
  - Successful implementation requires face-to-face training of providers for interventions
- Support, retention and continued quality of health promoters are persistent problems
  - potential solutions include community incentives, recognition, materials and small gifts
- Professionalizing community health promoters could improve training and retention, although there are disadvantages to this approach

#### 3. Surveillance and disease monitoring and the barriers to implementing effective cancer registration

Marion Piñeros, Programme of Action for Cancer Therapy (PACT), International Atomic Energy Agency, Vienna, Austria,

and *Iván Chávez*, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru

Cancer information is a key element of cancer control planning and evaluation; without appropriate and valid information, public health strategies will be based on poor foundations and the effectiveness of investments will be difficult to ascertain. Cancer registries play a fundamental role in providing incidence data for cancer control.

There are enormous differences between HICs and LMICs in terms of the development of cancer registries and the quality of information produced. While the population covered by cancer registries that were included in the last edition of Cancer Incidence in Five Continents reached 95% in the USA, it only reached 8% and 2% for South America and Africa, respectively (2). In light of the challenges for comprehensive cancer control and the recently adopted targets and indicators of the NCD Global Monitoring Framework (5), there is a need to strengthen cancer registration in LMICs.

Based on successful experiences, the workshop explored key aspects for successful initiation, implementation and sustainment of cancer registration and surveillance. Another important aspect was to provide and share ideas and strategies to ensure effective dissemination and use of information from cancer registration and surveillance by key stakeholders and decision-makers.

**Abstract 1: Strategy for the standardization of regional cancer registries and improvement of their quality in Japan**

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**Background**

In Japan, cancer registries have been developed independently by each prefectural government, and there exist many different database systems and registration methods. To solve this problem, we formed a research group (JCSRG) and started to standardize cancer registries in 2004. Considerable success was achieved and development of relevant systems to improve the quality of data collected and to widely inform citizens of the information derived from the registries was initiated.

**Methods**

JCSRG consists of the researchers from the National Cancer Centre and regional cancer registries. JCSRG achieved standardization by dividing the 10-year strategy for cancer control by the Ministry of Health, Labour and Welfare into three components: (1) the development and establishment of standard procedures and a database system; (2) the promotion of standardization and improvement of data quality; and (3) the establishment of a method to achieve the objectives of population-based cancer registries.

**Results**

Initial training was provided by the JCSRG at the cancer registry central office in prefectures that have adopted the standard registry system. This led to a distinct improvement in standardization and a rapid increase in adoption of the standard system is expected. By June 2013, 41 of 47 population-based cancer registries in Japan had adopted this system.

**Conclusions**

It is essential to acquire accurate cancer incidence data to conduct accurate analyses for cancer control. The standardization of population-based cancer registries in Japan is almost complete, transferring emphasis on to enhancement of registry data quality and to methods of widely promulgating the results. Various systems related to the cancer registries, such as the hospital-based cancer registry system, the survival confirmation system using the Governmental Basic Residential Registers Network System, and the web-based cancer statistics system, are being developed.

**Abstract 2: Surveillance based on cancer registries to improve cancer control**

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Cancer is the leading cause of death in developed countries and with the decline in mortality from cardiovascular diseases in developing countries will become the leading cause of morbidity and mortality in all continents. Information on the cancer burden is essential for research, planning and evaluation of control programmes. Surveillance is a crucial component for planning effective and efficient cancer control programmes and monitoring and evaluating

their performance. One of the indicators proposed by the Global Alliance for Control of Non-Communicable Diseases is the incidence of cancer by type. In Brazil, population-based cancer registries (PBCR) in 27 cities are a major resource for cancer surveillance. Incidence, mortality and morbidity data are essential for disease control, establishing organizational networks and setting priorities for cancer control. This study presented seven major types of cancer and examined the mortality/incidence ratio (M:I), as an indirect measure of cancer survival by sex. Tumours with better prognostics were prostate and breast cancer followed by cervical and bowel. The worst prognosis occurred for stomach and lung cancer. Survival was similar to that observed in developing countries. Population-based survival studies are essential to evaluate population access to health services and to reinforce the role of PBCR in establishing public policies and improving the health conditions of the population.

*Abstract 3: A centralized hospital-based cancer registry in Argentina - a useful tool for population-based cancer registries data improvement*

*María G Abriata, Instituto Nacional del Cáncer, Ciudad Autónoma de Buenos Aires, Argentina*

#### Background

The main objective of Argentina's Institutional Tumours Registry (RITA-Registro Institucional de Tumores de Argentina) is to record the personal data of cancer patients in a continuous, systematic and complete way, document pathological features of the tumours, collect clinical details of treatment and follow-up to provide information and analyse cancer care in health services.

#### Methods

The software is organized in five modules or Data Dimensions (DD) based on the health care pathways made by cancer patients in their own continuum of care:

- ▶ **DD1:** personal and demographic data of patients;
- ▶ **DD2:** "tumour data" coded by ICD-O-3 (it is also possible to record immunohistochemistry, hormone receptors results if available, co-morbidities and performance status);
- ▶ **DD3:** enables input of all consecutive patient treatments (intention, strategy and response description), in the reference institution or another hospital;
- ▶ **DD4:** comprises two parts: tumour follow-up (with/without relapse) and patient follow-up until death from this disease or another cause; and
- ▶ **DD5:** enables systematic epidemiological analysis.

#### Results

Programming RITA was one of the main tasks carried out since the National Cancer Institute was established in September 2010. It was conceived as a centralized information system on a web platform, where data are stored in relational databases. During the loading process, data are validated with a set of parameters to ensure completeness and accuracy. Throughout 2011, data were loaded into the software as a pilot test. RITA was implemented in 21 institutions from 11 provinces, with 4,258 patients and 3,518 tumours registered to date.

#### Conclusion/discussion

Personnel for data entry are being hired throughout the country to improve data entry and we are working on a specific export processes for population-based cancer registries. Using registries to inform national cancer policy ensures optimal utilization of resources for cancer control programmes. RITA software has proved to be useful for reference hospitals in Argentina providing them with their own cancer registries.

#### Box 3: Summary and recommendations from Workshop 3

- ▶ Political will and resources are important to start, maintain and expand cancer registries
- ▶ Ministries/national institutes can play a key role in fostering and supervising the development of registries
- ▶ The WHO Global Monitoring Framework provides motivation for collecting data
- ▶ When developing registries, it is important:
  - to have short-, mid-, and long-term plans
  - to have standardized procedures
  - to have/use available technologies and have support for these technologies
- ▶ Once established, sustainability of registries:
  - can be improved through continuous training, monitoring and audits; this can also increase motivation
  - requires dedicated long-term personnel
  - can be supported through collaboration among different stakeholders
- ▶ Translating data into information and periodic communication of results to key stakeholders and decision-makers is essential if policy change is to be enacted

#### 4. Surveillance of risk factors: Understanding cancer-related exposures to impact research and prevention activities

*Raul Hernando Murillo Moreno, Instituto Nacional de Cancerología, Bogotá, Colombia and Edgar Amorin, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru*

The World Health Organization estimates that about one third of all cancers are preventable (12), one third could be cured through early detection and timely treatment, and for one third of cancers palliative care is the only option. Prevention is clearly the most cost-effective, long-term approach and should be promoted and strengthened, particularly in LMICs. The burden of cancer due to different risk factors varies across populations, but globally the most relevant risk factors for cancer are tobacco consumption and exposure, physical inactivity, obesity, diet, alcohol use, infections and environmental exposures either in the workplace or the environment.

Risk factor control should be accompanied by proper surveillance to determine the magnitude of the risk and the attributable burden of disease. Thus, surveillance is critical for informing policies and programme development for cancer prevention, and to support monitoring and evaluation of prevention strategies. Despite its relevance, many countries do not have strong surveillance systems and very little usable data on risk factor exposure; additionally, data on risk factors for chronic conditions such as cancer are frequently not integrated into national health information systems. Consequently, improving surveillance and monitoring must be a top priority for cancer control.

This workshop focused on the limitations and opportunities for developing cancer risk factor surveillance systems in LMICs.

**Abstract 1: Evaluation of occupational exposure to benzene in Rio De Janeiro, Brazil: A health situation study of gas station attendants**

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In Brazil, gas station attendants are occupationally exposed to benzene by inhalation or dermal absorption during their

working process. Benzene is an important pollutant compound, present in both occupational and general environments. Besides well-established acute effects, benzene is a recognized Group 1 carcinogen (IARC). Chronic exposure to high concentrations of benzene in humans is associated with an increased incidence of myelodysplastic syndrome and acute myelogenous leukemia. This study was undertaken to evaluate gas station attendants' exposure to benzene and to identify clinical alterations and haematologic effects of chronic benzene poisoning in exposed workers. The study population comprised 117 gas station attendants who were employed at six gas stations in Rio de Janeiro, Brazil. Sociodemographic and clinical data were collected. From each subject, a urine and venous blood sample was collected for exposure assessment. Haemoglobin, haematocrit, platelets, white blood cell count, lymphocytes and neutrophils were measured. Chromosomal aberrations in peripheral blood were examined by FISH assay. Risk habits of gas station attendants identified during the study were: the use of rags soaked with gasoline in direct contact with the skin (80%), placing the face in proximity to the fuel tank (37%), sucking fuel with the mouth (34%) and wearing a uniform soaked with gasoline during the workday (34%). Workers reported visual alterations (42%), osteoarticular (27%) and otorhinolaringologic (18%) diseases, and gastrointestinal (14%) and respiratory (14%) problems. Furthermore, 37% of women attendants had miscarriages and 18% of all attendants presented haematologic alterations indicating benzenism. Urine sample and chromosomal analysis is still in progress. Together these preliminary results indicate that gas station attendants' occupation brings potential risks to workers health due to exposure to benzene.

**Abstract 2: Acceptability of self-collected vs. provider-collected sampling for HPV DNA testing among women in El Salvador**

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*Miriam Cremer, Basic Health International, San Salvador, El Salvador and University of Pittsburgh School of Medicine, Pittsburgh, PA, USA*

#### Objective

To determine the acceptability of self-collected vs. health care provider-collected sampling among women who participated in a public sector HPV-based cervical cancer screening programme in El Salvador.

#### Methods

In a study of women aged 30–49 years in which provider- and self-collected specimens were collected and tested by careHPV™ (Qiagen, Gaithersburg, MD, USA), a random sample of women were asked to respond to a survey at the end of their visit. The survey solicited participants' preference for self- vs. provider-collected sampling, in addition to previous cervical cancer screening history, knowledge of HPV and cervical cancer, HPV risk factors, and demographic information.

#### Results

There were 518 women enrolled in the study, of which 142 (27.4%) had not received cervical cancer screening within the past three years and were considered under-screened. Overall, 38.8% preferred self-collection, 31.9% preferred provider-collection, and 29.3% had no preference. Preference for self-collection was associated with prior tubal ligation, knowledge of HPV, a preference for future self-sample collection and a preference for future screening to take place at home ( $p < 0.05$ ). Preference for self-collection among under-screened women was not statistically significant ( $p = 0.11$ ). The most commonly cited reasons for self-collection preference were privacy/embarrassment, ease and less pain; the reasons cited for provider-collection preference were result accuracy and the provider's knowledge and experience.

#### Conclusions

Our findings suggest that self-sampling is an acceptable collection method and that future cervical cancer screening programmes could consider offering this option to women either in the clinic or in their home. While future investigation of self-sampling preferences among under-screened women is needed, a programme allowing women to self-sample at home may increase screening coverage among women in developing countries who are not participating in current cervical cancer screening programmes and reduce the burden that screening places upon the clinical infrastructure

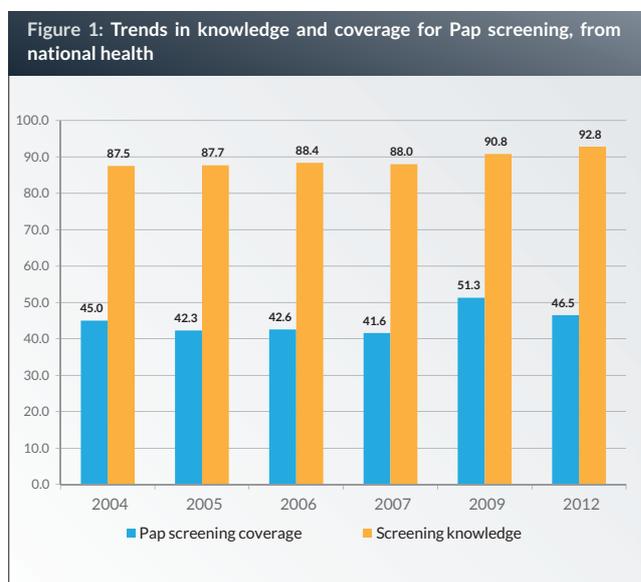
in these low-resource settings.

#### Abstract 3: Trends in knowledge and coverage for cervical cancer screening in Peru: Analysis of the health national survey 2004–2012

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Cervical cancer is the leading cancer in Peruvian women with an incidence rate of 34.5 cases per 100,000 (age standardized rate). While a cancer control programme has not always been established, several important actions for early detection of cervical cancer have taken place, including screening with Pap smears, non-systematic information spread, improvement of health services and others. These actions have been implemented more intensively since 2002 and in recent years the National Programme for Cancer Control has been better established. The Peruvian national survey about demography and health has its origins in the mid-1980s, and since 2004 has included some questions about health knowledge, including cervical and breast cancer screening. This work analyses trends from 2004 to 2012.

We found an increasing trend in women's knowledge about cervical cancer screening (87.5% in 2004 to 92.8% in 2012) (Figure 1). However, there was no change in the



proportion of women receiving a Pap test (45.0% in 2004 to 46.5% in 2012). Variations in geographical origin and educational level were consistent in all surveys. Women from Lima and the coastal region and women with a higher education level had better screening coverage.

These data represent a base and transitional period in a cervical cancer control process. Improved health services require an organized screening programme for cervical cancer and women need to know that screening is necessary, despite the challenge of low motivation. These indicators should improve in the next few years with the recent introduction of a more comprehensive cancer control programme.

#### Box 4: Summary of Workshop 4

- Surveillance of risk factors is critical for informing the development of policies and disease control programmes
- Risk factors to be surveyed should be tailored to the setting as their importance may differ by country and region
  - \_ occupational exposures identified among countries represented in the workshop: hydrocarbons, metals from mining, pesticides, tobacco, asbestos, motor vehicle exhaust
- Good quality data on risk factors is lacking in many countries
  - \_ the extent of infectious causes of cancer (e.g., hepatitis, *H. pylori*, HPV, EBV) remains unknown in many regions due to suboptimal data
- Risk factor surveillance should be conducted separately for adults and adolescents as behavioural risk factors differ between these groups
  - \_ smoking initiation may be different in these age groups which may inform tobacco cessation programmes
- Many Latin American countries gather information on risk factors through national surveys; efforts to improve, strengthen and share surveys should be made to ensure that the information is complete and of good quality

## Discussion and conclusions

*David Forman, International Agency for Research on Cancer (IARC), Lyon, France and Carlos Santos, Instituto de Enfermedades Neoplásicas (INEN), Lima, Peru*

All countries face the challenge of changing population demographics. Additionally, LMICs disproportionately face increasing exposure to adverse risk factors (primordial and primary) and late presentation with advanced stage, incurable disease. This situation highlights the problems of limited access to health care (poorly developed or absent universal health coverage), limited public and population health measures, including organized screening programmes

to detect pre-clinical (early stage) curable cancer (or other noncommunicable diseases (NCDs)), and health care delivery systems challenged by availability of qualified personnel, technologies, equipment, facilities and financing.

One third of cancers are considered preventable, with 2–15% of cancers potentially caused by environmental exposures: 5–30% of the working age population may have been exposed to lung carcinogens, accounting for 10% of lung cancers worldwide (12). Surveillance systems for occupational cancer are scarce in LMICs, being technically and financially challenging; policies and regulations for controlling occupational cancers are weak and limited by complacency.

Infectious agents are responsible for 22% of cancer deaths in LMICs and 6% in HICs (13). The burden of liver, cervix, oral-pharyngeal and ano-genital cancer due to HBV and HPV can be substantially reduced through vaccination programmes, given awareness, accessibility and affordability of vaccines.

Tobacco use and exposure, physical inactivity and alcohol consumption account for the largest burden of cancer worldwide. Tobacco use is the single greatest avoidable risk factor for cancer mortality (22% of all cancer deaths per year). A further 22% of oral cavity and oro-pharyngeal cancers are attributable to alcohol. All these factors have relevance to other NCDs.

National programmes for cancer and NCD control need prevention and surveillance strategies to reduce the prevalence of occupational, environmental and behavioural risk factors. Population-based surveys, relevant in terms of country content and context, appropriately designed, conducted and financed are an essential component of cancer/NCD control planning and evaluation of implemented interventions, notwithstanding the challenges of data validity, coverage, subpopulations (e.g., youth and indigenous populations) and the infrastructural, technical and cost constraints of LMICs.

One third of cancers could be cured through early detection and timely treatment, either as pre-clinical or early-stage lesions. Within the Latin American region, countries have different screening tests and technologies, with variation between and within countries. There is controversy regarding data, recommendations and consistent use of evidence to inform policy. Circumstances vary within and between countries, necessitating alignment of interventions to national acceptability, feasibility and practicality. Population interventions of proven efficacy to prevent or detect early-stage liver, cervix and colon cancer, and potentially for those at high risk of lung cancer, exist.

Latin America presents the opportunity for regional “harmonization” of practices according to national contexts through collaboration and regional policy development.

Training of health care workers for cancer and NCD control is a recognized challenge for Latin America, for which innovative solutions are being sought. In addition to the traditional academic and professional discipline-based education and certification programmes, the need to train community practice-based workers has been identified along with the adaptation of communication techniques, messages and support systems to reach target audiences. Important elements are the integration of health initiatives through existing community leadership, forums, and events; through personal “face-to-face” interactions and practice; through full engagement of the community with the development of health policy and practice; and through development of incentives to recognize and reward the activities and commitment of community health workers, including potential “professionalization” of their role.

For a disease that arises in health, covers the continuum from prevention to palliative and end-of-life care, requires a multiplicity of screening, diagnostic, treatment and palliative elements, and constitutes the single greatest population disease burden worldwide, any effort for control requires a strategy (a population-based cancer control plan) that is based on knowledge of the burden of disease (“the need” – incidence, prevalence, morbidity, mortality, stage distribution, treatment), the availability and capacity for

interventions (“capacity”) and the impact of interventions). The rational use of resources (e.g., human, technical, equipment, facilities and financial) mandates the necessity to prioritize allocation and, ultimately, to define the value obtained (both absolute and relative cost-effectiveness). Disease registries are a fundamental requirement to enable effective disease control, to ensure appropriate resource allocation, and to demonstrate the value of resource investment. With full appreciation of the resource challenges of LMICs for initiation, maintenance and sustainability of population-based disease registries, the “step-wise”, incremental development of a registry is an indispensable requirement for national and global cancer control.

#### Acknowledgments

*This manuscript is a synthesis of plenary presentations, workshop discussions, including selected abstract presentations, and recommendations for ongoing actions derived from Session 3 of the Fifth International Cancer Control Congress (ICCC-5) held in Lima, Peru, 3-6 November 2013. The ICC-5 working group was made up of Simon B Sutcliffe, Kavita Sarwal and Catherine G Sutcliffe from the International Cancer Control Association and Tatiana Vidaurre Rojas and Roxana Regalado from the National Cancer Institute (INEN) in Peru. The opinions expressed herein represent those of the authors alone and do not necessarily represent the institutions and organizations by which they are employed.*

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# THE FIFTH INTERNATIONAL CANCER CONTROL CONGRESS

## SESSION 4: IMPROVING INTEGRATED APPROACHES TO CANCER TREATMENT AND CARE

# SESSION 4: IMPROVING INTEGRATED APPROACHES TO CANCER TREATMENT AND CARE

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Cancer is a global and rapidly increasing, but not uniform problem. Access, quality of care and efficiency of cancer services are challenges in low- and middle-income countries, where an increasing proportion of burden is occurring. Yet, the health systems of these countries are particularly unprepared and ill-equipped to deal with this growing burden and chronic nature of cancer and other noncommunicable diseases. Investment in the health care systems in these countries is required, but given limited resources, health services researchers and policy-makers must explore how these much-needed investments can be best directed for optimal results. There is a need to implement radical changes in the social/political environment and increase access to primary care that, combined with well-designed and affordable disease control programmes, can improve cancer care and control in developing countries. The lack of information on the economic efficiency of most cancer treatments and many preventive measures is of note in these regions but it is imperative to challenge the assumption that cancer care is impossible or too costly in poor countries. Investment in cancer care and control can improve global health.

*Key words: cancer, access to treatment and care, developing countries, health system*

## Introduction

*Rolando Camacho, Program of Action for Cancer Therapy, International Atomic Energy Agency, Vienna, Austria, and Claudia Naylor, Instituto Nacional de Cancer, Brazil*

More than half (56%) of the 11 million new cases and two-thirds (64%) of the approximately eight million deaths from cancer per year occur in low- and middle-income countries (LMICs). This disproportionate burden is due to increasing incidence (population increase, ageing and risk factor exposure associated with poverty, circumstance and “Westernization”) along with reduced premature mortality from infectious, communicable diseases. Despite an increasing majority share of the burden, the proportion of global resources directed to cancer in LMICs is less than 6% (1–13).

Investment in health care systems in LMICs is required. However, how this needed investment can be best directed to achieve optimal outcomes requires considerable attention. Three areas of particular relevance are:

- ▶ risk factor control and primary prevention (Session 1, ICCC–5);
- ▶ early detection of cancer and NCDs (Session 3, ICCC–5);
- ▶ access to health services and systems and support for treatment and care.

LMICs are particularly unprepared and ill-equipped to deal with the growing burden and chronic nature of cancer and NCDs. Notwithstanding, enhancing global cancer control requires that they be able to respond to the increasing burden of cancer and NCDs through universal coverage of health systems and through ways that have relevance to socioeconomic sustainability for both LMICs and HICs.

## Methodology and objectives

ICCC–5 Session 4 on “Improving integrated approaches to cancer treatment and care” comprised three plenary presentations providing an overview of the subject matter as a means of preparing Congress participants for participating in four, small group, interactive workshops on relevant topics to be addressed in greater depth. Selected abstracts providing particular insights into the topic area were presented orally by the authors in each of the workshops. Workshop leaders were encouraged to conclude their workshops with a brief set of prioritized recommendations to identify the key directions for further development of interventional activities beyond this Congress.

The objective of this session was to explore integrated approaches to interventional treatment, management and

care of the patient based on global and Latin American experiences. The following four issues were selected for in-depth discussion in the workshops:

- ▶ Multidisciplinary approach for cancer treatment and care.
- ▶ Building palliative care.
- ▶ Improving access to treatment and care.
- ▶ Mobilizing communities.

## Plenary presentations

### 1. Alternative models of care

*Franco Cavalli, Oncology Institute of Southern Switzerland, Bellinzona, Switzerland*

In the last 15 years our understanding of the biology of cancer has increased tremendously and the speed with which we acquire new knowledge about the basic biology of neoplastic diseases is currently increasing even further. Through translational research, some of this knowledge has been transferred into new and more efficacious treatments. Together with intensified preventive efforts and improvements in early detection, these new treatments have contributed to the relative decline of overall cancer mortality, which we are currently witnessing at least in the most developed countries. Even there, however, costs of new treatments have reached a level which is no longer sustainable for most health care systems. On a global scale, the explosion of new cancer cases in low- and middle-income countries (LMICs) (4) has resulted in a rapid increase in the worldwide burden – 11 million new cancer cases and seven million cancer deaths in 2000. If current trends continue, 25–26 million new cancer cases and 13–14 million cancer deaths could occur by 2030. Although we are about to “conquer cancer” from a medical and scientific point of view, the war may be lost on a global scale if we are not able to implement radical changes in the social/political environment (5,15). Some of these changes (summarized in the appeal “Stop Cancer Now”(16)), require implementation on a macroeconomic scale, for example, the development of new business models for the development of new anti-cancer treatments that should substitute current treatments that are no longer acceptable or sustainable. Other required changes will have to concentrate on alternative models of care. However, any possible model of care requires improvements and strengthening of public health care systems, which, alas, have been weakened during the last 20 years in most developing countries. Without such improvements, it will be impossible to tackle the “looming cancer disaster” which has been forecast for the majority of developing countries.

## 2. Universal health coverage and the challenge of responding to chronic illness: A case study of Mexico and breast cancer

*Felicia M Knaul, Harvard Global Equity Initiative, Global Task Force on Expanded Access to Cancer Care and Control, and Tomatelo a Pecho AC, Mexican Health Foundation, Mexico and Canada*

Emblematic of the Latin American region, and other low- and middle-income countries (LMICs), Mexico is in the midst of a protracted and polarized epidemiological transition which creates a double burden of infectious and noncommunicable diseases. The cancer transition mirrors the overall epidemiological transition so that LMICs increasingly face both infection-associated cancers, as well as all other cancers. This burgeoning health priority risks overloading resource-strapped health systems if they are not redesigned to respond to the increasingly chronic nature of disease (7,9).

Despite the common belief that cancer is a disease of rich people and countries, LMICs bear a disproportionate share of preventable suffering and a majority share of the global burden of cancer – 58% of new cases reported in 2008, with an expected increase to 70% by 2030. Yet, the health systems of these countries are particularly unprepared and ill-equipped to deal with the growing burden and chronic nature of cancer and other noncommunicable diseases.

Research done by the Global Task Force on Expanded Access to Cancer Care and Control (<http://gtfccc.harvard.edu>) has shown that cancer care can be effectively incorporated into universal health insurance packages in ways that benefit and strengthen the entire health system. Expanding cancer care through a diagonal approach and within the context of universal health insurance – using priority disease-specific interventions to drive improvements in the health system – can expand coverage and improve access across diseases and populations (9).

Further, our evidence demonstrates that many of the key interventions for prevention as well as treatment are much less costly than is often assumed and that inaction far outweighs the costs of effective action. Specifically, the cost of prevention and treatment for cancer is less than the value of lost productivity, and global savings can be in the hundreds of billions of dollars. Further, the costs of some key interventions for LMICs such as the HPV and HBV vaccines have dropped as a result of introducing global financing platforms.

Several LMICs have identified solutions and included cancer care and control in their national health insurance programmes, including Mexico (8), Peru, the Dominican

Republic, Colombia, and others. In Mexico through the Seguro Popular, treatment for all cancers in children, breast cancer, and several others are covered. Preliminary results suggest that the inclusion of breast cancer in Seguro Popular has relieved the financial burden and risk for families and expanded access for the most vulnerable. For example, prior to the inclusion of breast cancer in Mexico in 2007, approximately 30% of women diagnosed at the National Institute of Cancer of Mexico abandoned treatment within a year – the majority for lack of financial resources to cover treatment. In 2010, the rate of abandonment was less than 1%, while the number of women being treated increased by 50%.

It is imperative to challenge the assumption that cancer care is impossible or too costly in poor countries, just as was successfully done with HIV treatment more than a decade ago, and redesign health systems to respond to the challenge of cancer and other chronic conditions. Not only is cancer control and care not impossible in LMICs, it provides an opportunity for strengthening health systems to respond to the increasing burden of noncommunicable and chronic disease and achieve universal coverage of health systems (7).

## 3. Using cancer registry data for cancer treatment planning and implementation at a national level

*Jorge Luis Soriano García, Medical Oncology Department of Ameijeiras' Hospital, Cuba*

The overall incidence of cancer in developing countries is half that of the developed world, but it is increasing rapidly. In contrast, the mortality of cancer is already comparable between the developing and developed world and site-specific survival rates in developing countries are often less than one third of those in the developed world.

Access to cancer treatments is one of the areas of greatest need in the developing world. Initial chemotherapy regimens are often the most important for determining therapeutic outcome, but in contrast to the developed world, most drugs are paid for privately in developing countries. Burdened with much of the liability for funding cancer care, governments (public) and private health care payers are alarmed by the unprecedented and prohibitive rates at which costs are increasing. For effective treatment, chemotherapy should not be delayed, and evidence-based programmes should be used, even if these require more treatments and more frequent cycles. Therapies emerging today reflect deeper understanding of growth factor binding, signal transduction, transcription, cell cycle control and apoptosis. These targeted therapies, while highly effective and often having favourable

side-effect profiles, are prohibitively expensive in most developing countries. Only a few therapeutic programmes are available to offer these new options to the poor.

Little is known about other cancer-related outcomes in developing countries, such as toxicity of treatment, quality of life, patient satisfaction, equity and economic efficiency. The lack of information on the economic efficiency of most cancer treatments and many preventive measures is of note, as resources are limited in developing countries and choosing the most cost-effective measures is a very important consideration.

Investment in health care systems in developing countries is required. For oncology, this includes developing a sustainable supply of trained oncology professionals, expanding the supply of treatment equipment, improving drug supply, physical infrastructure and organizational infrastructure for cancer control. Given limited resources, health services researchers and policy-makers must explore how these much-needed investments can be best directed for optimal results. This will require cancer-related health services research with broad local and international collaborations in addition to long-term investment from all parties. The need for better health monitoring and evaluation data in developing countries is widely recognized. Targets set by the International Union Against Cancer (UICC) World Cancer Declaration 2008 include improved measurement of the global cancer burden and measurement of the impact of cancer control interventions.

Common information sources in developing countries provide information on many disease types. Population-based cancer registries collect information on vital status, occurrence and treatment of different types of cancer and provide the “backbone” needed to perform a wide range of oncology health services research. Population-based information on cancer cases can be linked to other population-based and hospital-based health data sources to provide a rich tapestry of information on structure, process and outcome of cancer prevention, screening, palliation and treatment. There are still many developing countries without a cancer registry of sufficient quality. For instance, the population coverage by cancer registries of sufficient quality for inclusion in the International Agency for Research on Cancer’s (IARC) 2007 report on global cancer incidence was 1% for Africa, 4% for Asia and 4% for South and Central America. This compares to 33% in Europe and 80% in North America.

Registry information contributes to locally-relevant cancer system planning. By monitoring changes in needs and capacity for services, the health care system can respond more efficiently and sustainably. Collection of national health data

can also be helpful for comparison with other systems and countries; encouraging greater participation of the public and other parties in national and regional advocacy for changes to health policy; enabling effective advocacy for needed resources for national cancer control; and for accountability of parties involved in provision of cancer control to the public and funding agencies. Cancer registry data and health data are crucial for supporting national and regional research structure; for defining cancer research priorities, for instance, focusing research on cancers with the greatest burden of disease in the population or exploring the potential cost-effectiveness of a new cancer treatment or cancer control strategy; for providing an important tool in the local training of individuals in health policy, graduate level epidemiology and health services research, and for a rational process to help identify opportunities for knowledge translation and policy.

Finally, health data permits the audit of patient safety, quality control and outcome assessment of cancer control programmes. This includes trending changes in cancer incidence or survival over time and following geographic variations in incidence of a given cancer. Health data can help assess effectiveness, access to care, equitability of structure, process and outcome, sustainability and economic efficiency. With limited resources, achieving the greatest health benefit with available resources is an important outcome of health systems. The vast majority of economic analyses for cancer treatment, palliation, screening and early detection are from developed countries. Though there are clearly many cost-effective interventions that oncologists use in developed countries, their cost-effectiveness in specific resource-limited settings is usually not known.

The presentation was an example from Cuba describing the experience of planning and implementing cancer care services using data from the cancer registry and national treatment guidelines.

## Workshops

### 1. Multidisciplinary approach for cancer treatment and care

*Franco Cavalli, Oncology Institute of Southern Switzerland, Bellinzona, Switzerland, and Julio Abugattas, Instituto Nacional de Enfermedades Neoplásicas, Peru*

Knowledge about cancer has grown considerably in recent years, and, along with improvements in technology, has allowed for the development of better treatments. In developed countries, these advances have been applied in a coordinated way to cure, ameliorate symptoms or alleviate the burden for cancer patients. However, in low- and middle-income countries, these improvements have not been

achieved for several reasons: lack of political commitment, lack of money and lack of a more or less homogeneous social structure. All of these reasons make it difficult for these countries to adequately address the volume of cancer patients that are expected in the coming years, unless specific activities to mitigate this potential public health disaster are developed.

**Abstract 1: Cancer control in Ghana: Experience as a PACT Model Demonstration Site (PMDS)**

*Kofi M Nyarko, Ghana Health Service, Accra, Ghana*

Collaboration between Ghana and the International Atomic Energy Agency's (IAEA) Programme of Action for Cancer Therapy (PACT) began with the 2005 imPACT mission. The IAEA provided technical input to the Ministry of Health for a comprehensive proposal entitled "Building Comprehensive Cancer Control Capabilities in Ghana". Ghana was designated a PACT Model Demonstration Site in September 2009.

By 2011, Ghana had achieved the following in cancer control: a National Cancer Control Steering Committee was formed through which the National Strategy for Cancer Control in Ghana 2012–2016 was developed. Working groups of the Steering Committee are currently implementing priority actions of the national cancer control plan. Ghana secured loans for more than US\$ 13 million dollars for civil works, equipping and training radiotherapy and nuclear medicine services at the two teaching hospitals in Ghana and also for public health activities such as cancer prevention, early detection and palliative care activities. This illustrates that Ghana can obtain funding for cancer control. The two comprehensive cancer centres, Korle-Bu Teaching Hospital in Accra and the Komfo Anokye Teaching Hospital in Kumasi have approved upgrading plans based on the long-term loan.

Ghana has also become one of the four pilot countries, along with Uganda, Tanzania and Zambia, selected for the Virtual University and Regional Training Network for Cancer Control (VUCCnet) project. The VUCCnet project is designed to improve the African regional capacity to deliver quality cancer control education and training using existing infrastructure, expertise and appropriate e-learning technology.

Screening is offered for major cancers but the coverage is limited. The two national cancer centres in the country offer comprehensive cancer services including radiotherapy. A large proportion of cancer cases in Ghana still present with late-stage disease and are eligible for palliative care. Unfortunately, palliative care services are limited.

**Abstract 2: Multidisciplinary teams (MDTs) in cancer care: A systematic review of the evidence**

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**Background**

Multidisciplinary teams (MDTs) are considered the best approach to organizing care in a way that brings together all the medical specialists involved in cancer diagnosis and treatment. This has led to many cancer plans incorporating MDTs. The aim of this study was to assess the evidence supporting the impact of MDTs on physician practice patterns and patient outcomes in cancer care.

**Materials and methods**

A systematic review of the literature was conducted. Fifty-one papers were extracted from the literature published from November 2005 to December 2012.

**Results**

Fifty-one papers were included, 29 focused on patient management and MDT and 22 on evaluating organizational components.

MDTs have been shown to improve clinical and process outcomes in cancer-patient management, even though evidence of a causal relationship between this type of intervention and outcomes is still limited. A wide variation in the types of tumours studied has been reported (breast with nine and colorectal, head and neck and prostate with six were the most frequently analysed), along with the fact that the scope of the MDTs' work extends to the entire process of care.

**Conclusion**

Different formats of MDT organization were found, such as meetings, clinics and online conferences. These organizational patterns are nonetheless driven by the need to align the clinical dimension (effective access to multimodal treatments and palliative care) with the patient-management dimension (MDTs' working roles and consistent communication between patient and team). More research should be done in the population-based assessment of the impact of MDT on the outcomes of cancer care.

**Abstract 3: Comprehensive care model for hospitalized, adolescent, oncology patients in Lima, Peru**

*Abel Limache-García, Tatiana Vidaurre Rojas, Gladys Lituma Aguero, Lili Ordonez Espinoza, Laura Urrunaga Linares, Yolanda*

*Sovero Torres and Olga Pineda Cortijo, Instituto Nacional de Enfermedades Neoplásicas (INEN), Peru*

### Introduction

Adolescents are neither children nor adults. They have specific psychosocial characteristics. Before 1994, at the National Cancer Institute of Peru (INEN), adolescent patients were hospitalized with either children or adults, but due to a lack of adaptation and motivation, an exclusive service was established.

### Objective

To provide high-quality, multidisciplinary, comprehensive, integrated care, focusing on psychosocial aspects of adolescents through interventions that facilitate adherence to treatment and ensuring a better quality of life and survival.

### Methodology

The Adolescent Unit responds to the health requirements of teenagers. In 1994, INEN with the Minister of Economy obtained international cooperation for the creation of the Teen Assistance Program in Extreme Poverty. INEN became one of the few public institutions worldwide with an exclusive service, whose goal is directed to the disease and to the challenges of development for teenagers with cancer.

### Medical intervention

Patients receive specialized care with different medical departments integrated within the multidisciplinary team.

### Social worker intervention

With a focus on poor teenagers and family disintegration, efforts are directed to the patient and family using internal and external networks.

### Nursing practice

Nurses monitor the compliance with the different components and provide opportunities for continuing education, leisure and motivational activities that allow teens to be optimistic in an environment offering security, affection and tranquility during treatment and promoting self-care during hospitalization and after discharge at home.

### Results and conclusions

Adolescents have a specific area for treatment, receiving health care from a multidisciplinary team of physicians, nurse practitioners, social workers and psychologists. This Unit has 39 custom-designed beds for patients 14–23 years old. The INEN Adolescent Unit has provided specialized integrated

health care for adolescents with outstanding results.

#### Box 1: Recommendations from Workshop 1

- ▶ Work should be multidisciplinary, but there is no clear or standard definition of multidisciplinary
- ▶ The costs and benefits associated with instituting multidisciplinary teams should be weighed
- ▶ Interdisciplinary teams should consider including members from NGOs, civil society and volunteers

### Summary of discussion by participants

The challenges inherent in multidisciplinary care comprise:

#### Care

Ensuring access to different treatments; creating multidisciplinary groups of health care providers, but allowing enough flexibility in their performance to make it cost-effective; prioritizing pathologies by incidence, including palliative care and improving access to opioids for pain control; rationalizing the use of different resources; and taking into account the sociocultural characteristics of each locality in decision-making and prioritization.

#### Education

Building capacity for population and health personnel.

#### Investigation

Strengthening data collection and favouring the formation of records for planning and resource allocation.

#### Advocacy

Mobilizing society to reduce the impact of the burden of this illness.

## 2. Building palliative care

*Gaspar Da Costa, Palliative Care Program, Ministry of Health, Panama, and Gillian Fyles, BC Cancer Agency, Canada*

It is projected that by 2030 the developing world will account for 70% of new cancer diagnoses and already almost two thirds of the world's annual cancer deaths occur in low- and middle-income countries (17). The majority of cases in the developing world will present with advanced disease and palliative care is vitally important for these patients and their caregivers, including access to opioids for pain relief. Cleary et al recently reported that in most of Latin America and the Caribbean, opioids availability continues to be low (18). The recent WHO Global Monitoring Framework includes morphine consumption per death from cancer as a palliative

care indicator, which is a major step forward in ensuring one key component of adequate palliative care is measured, however other indicators are also necessary. Significant gaps remain at all levels of the health care system worldwide.

This workshop highlighted key themes in the development of adult and paediatric palliative care internationally, and particularly in Latin America, including access to opioids and opportunities to develop programmes across sectors with government and NGO involvement, with a focus on primary health care.

*Abstract 1: How well are we addressing the needs of patients with advanced cancer? A report on the status of palliative care in Latin America*

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Noncommunicable diseases (NCDs) are the main cause of mortality and disability worldwide, including Latin America (LA) and the Caribbean.

Sixty-three percent of the 57 million deaths that occurred in 2008 were due to NCDs, of which cancers comprised 48%.

Palliative care (PC) aims to achieve the best quality of life for patients with advanced, progressive diseases and the relief of symptoms and suffering. The control of NCDs requires an integration of services, including prevention, early detection, diagnosis, treatment, rehabilitation and palliative care. There is considerable information available on prevention and curative services, but very little on the status of PC in LA.

Between 2010 and 2012 the Asociacion Latinoamericana de Cuidados Paliativos (ALCP) developed an Atlas on Palliative Care to evaluate the status of PC in Latin America. The Atlas was developed by implementing a survey of 59 PC providers in 19 countries of the region.

Results indicate that there are a total of 1.63 PC services per million inhabitants. Of these, 56% are provided in primary care levels (home care, community services and hospices) mostly clustered in eight countries. There is significant variation in development and service provision within the region, with > 50% of the services located within Chile and Argentina.

LA accounted for 8.3% of the global consumption of opioids at 4.8mg/hab below the global mean of 5.9mg/capita.

Collaboration among prescribers and drug regulators was reported as fair, ranging from very bad (Bolivia) to very good (Costa Rica).

Very few countries have PC laws and national plans/programmes (three and seven respectively). Thirteen reported having PC as a component of national cancer control programmes.

PC in Latin America needs to be developed further. Public policies and strategies need to be implemented to guarantee access to appropriate care for patients who no longer respond to curative treatments.

*Abstract 2: Integrating palliative care into a comprehensive paediatric oncology service in a tertiary cancer hospital - an Indian experience*

*Gayatri Palat, Two Worlds INCTR Cancer Collaboration, Vancouver, BC, Canada; Jagadeshwar Reddy, Two Worlds INCTR Cancer Collaboration, Vancouver, BC, Canada; Sudha Sinha, MNJ Institute of Oncology and RCC, Hyderabad, AP, India; Kannan T, MNJ Institute of Oncology and RCC, Hyderabad, AP, India and Stuart Brown, Two Worlds INCTR Cancer Collaboration, Vancouver, BC, Canada*

#### *Background*

Today, a child diagnosed with cancer in a developed country has an 80% chance of being cured. Unfortunately, this is not true for India where, of the 75,000 children with cancer every year, less than 20% survive. It is a challenge to implement appropriate strategies to take care of the growing trend in childhood cancer against a background of infectious diseases.

MNJ Institute of Oncology, a tertiary care hospital for the state of Andhra Pradesh, India, registers around 400 new children with cancer each year. The paediatric palliative care programme was started in 2007 with the aim of improving the quality of life children with cancer and their families.

#### *Objective*

To study the outcome of early integration of palliative care into a paediatric oncology programme.

#### *Methods*

Every effort is made to keep a child completely pain free and to incorporate palliative care from the time of diagnosis. The programme offers supportive care during the active curative treatment phase, palliative care in the advanced stage of illness, end-of-life care, procedural pain relief, psychosocial support, home-based care and regular consultations over the telephone. The results of the active support and

palliative care interventions in a paediatric oncology programme were analysed.

#### Results

- ▶ Increased numbers of children were treated, from 69 patient visits in 2006 to 278 new and 3,126 follow-up visits in 2012.
- ▶ Increased opioids consumption.
- ▶ Supportive care and implementation of a procedural pain relief protocol during curative treatment and a smooth transition to palliative and end-of-life care.
- ▶ Reduction in treatment abandonment, thus improving prospects for survival.

#### Conclusion

Early integration of palliative care into a paediatric oncology programme resulted in improvement in quality of life, smoother transition to palliative care and decreased treatment abandonment resulting in better survival prospects.

*Abstract 3: Improving integrated approaches to cancer treatment and care – how to build a successful palliative care programme in a low-resource setting*

*Zahra Lalani, British Columbia Cancer Agency and Two Worlds Cancer Collaboration Foundation, Burnaby, BC, Canada*

Andhra Pradesh (AP) is an Indian state with a population of over 65 million. Despite the perception of a thriving economy, the reality is that 68.7% of Indians live on less than US\$ 2 per day (World Bank, 2011). Established in the 1950s, MNJ Cancer Institute in AP is a 300-bed government-funded tertiary care hospital providing care to 10,000 adults and 1,000 children annually. Nearly 75% of these patients are in advanced stages at diagnosis and although India is a global exporter of morphine, 99.5% of Indian patients are not able to access this essential medication. Many barriers, such as governmental regulations, cultural beliefs, societal factors and lack of knowledge have contributed to unnecessary pain and suffering.

In 2006, the first Pain Relief and Palliative Care Program (PRPCP), based on the WHO Foundation Measures for Implementing Cancer Pain Relief Programs was established and integrated within MNJ Cancer Institute's existing infrastructure. This initiative was launched with the support of international and Indian NGOs and led by a visionary palliative care physician. As a result, pain medicines and palliative care became accessible to all patients at MNJ. Furthermore, in 2008, advocacy by the PRPCP led to

government policy changes to include palliative care in the health insurance scheme for people living below the poverty line. More than 12,000 new patients have been seen by the PRPCP since its inception and it has become a focal point for specialized palliative care training for other Indian states and abroad. Recently the programme extended its reach and brought palliative care closer to home with the development of home care services and outreach to rural villages. The vision is that the PRPCP framework may serve as a model for other international settings.

*Abstract 4: Evaluating government policies affecting cancer pain management and palliative care in Colombia, Guatemala, Mexico and Panama: Making progress to improve medication availability and patient care*

*Martha Alice Maurer, Aaron M Gilson, S Asra Husain and James F Cleary, University of Wisconsin Carbone Cancer Center, Madison, WI, USA*

Currently, about three-quarters of all cancer-related deaths occur in low- and middle-income countries, and this trend is expected to continue. For the majority of these individuals, symptom management (e.g., pain treatment) is insufficient because diagnostic tools and treatment methods are either non-existent or difficult to obtain. Untreated or poorly-treated pain has devastating consequences on patients' quality of life and functionality, particularly when the pain is severe or debilitating. Despite various treatment modalities, international health experts continue to regard potent opioids analgesics in the class of morphine, particularly orally-administered morphine, as the gold standard for treating moderate to severe cancer pain. Numerous international regulatory authorities have identified the presence of countries' legislation, regulations, and administrative policies, adopted to minimize drug diversion and abuse, as impeding the availability and accessibility of morphine and other opioids medicines for legitimate medical purposes. To provide an evidence base for this issue, a systematic, criteria-based evaluation of government policies affecting pain management was developed and applied to a sample of four Latin American countries: Colombia, Guatemala, Mexico and Panama. The criteria are applicable to policies from any country. All national laws governing drug control, as well as laws governing medical and pharmacy practice, were evaluated. Results from research presented at this conference represent policy content with the potential to either positively or adversely influence pain treatment, palliative care and the use of opioids pain medicines. This research is designed to enhance awareness of countries'

current legal provisions and their implications for health practice and patient care, including the need to remove undue restrictions or legal ambiguities. Supporting policy improvement with such evidence can help create a legislative and regulatory environment free of barriers to medication availability for cancer pain management and palliative care.

#### Box 2: Recommendations from Workshop 2

- ▶ Include palliative care as part of the continuum of care in policies of health and cancer plans
- ▶ Essential to have opioids available in all parts of each country
- ▶ Recognize palliative care as a human right

### 3. Improving access to treatment and care

*Rolando Camacho, Program of Action for Cancer Therapy, International Atomic Energy Agency, Vienna, Austria, and Claudia Naylor, Instituto Nacional de Cancer, Brazil*

The incidence of cancer is increasing globally, particularly in low- and middle-income countries (LMICs). The millions of cancer patients who will be diagnosed every year for the foreseeable future need access to optimum treatment, wherever they live, to improve their chances of survival.

New approaches to preventing and treating this disease are required. Fundamental challenges include: the limited availability of appropriate human, technical and physical resources; geographic restrictions; acceptable, affordable and compliant interventions; and societal awareness of the needs, challenges and opportunities for improved cancer control.

Several innovative strategies for reducing the impact of cancer in LMICs include the development of guidelines and customized protocols, establishment of cancer programmes and national or regional referral centres, increasing access to cancer early detection, use of telemedicine and health insurance reforms.

Increasing access to cancer care and control in LMICs is an equity imperative and expanding access requires a systems approach that includes priority-setting, price reduction, transparent information of prices and sources, quality assurance, cost-effective interventions, reinforcement of the role of cancer registries, engagement of national governments, community, civil society and private sector, and policies to address palliation, pain control and innovation.

*Abstract 1: Implementing a cancer fast-track programme between primary and specialized care in Catalonia, Spain: A mixed methods study*

*Josep A Espinas, Josep M Borrás and Joan Prades, Catalanian*

*Cancer Plan, Hospitalet Llobregat, Barcelona, Spain*

#### Background

The Cancer Fast-track Program's aim is to reduce the time that elapses between well-founded suspicion of breast, colorectal and lung cancer and the start of initial treatment in Catalonia, Spain. We aimed to analyse its implementation and overall effectiveness.

#### Methods

A quantitative analysis of the programme was carried out using data generated by the hospitals on the basis of seven fast-track monitoring indicators for the period 2006–2012. Also a qualitative study, based on 83 semi-structured interviews, was conducted with primary and specialized health professionals and health administrators to obtain their perception of the programme's implementation.

#### Results

In 2012, about half of all new patients with breast, lung or colorectal cancer were diagnosed via fast-track, though the cancer detection rate declined across the period. Mean time from detection of suspected cancer in primary care to the start of initial treatment was 27.5 days for breast, 30.5 for colorectal and 32.9 for lung cancer (2012). Professionals associated with the implementation of the programme showed that general practitioners faced with suspicion of cancer had changed their conduct with the aim of preventing delays. Furthermore, hospitals were found to have pursued three specific implementation strategies (top-down, consensus-based and participatory) which made for cohesion and sustainability of the circuits.

#### Conclusions

The programme has contributed to speeding up diagnostic assessment and treatment of patients with suspicion of cancer, and to clarifying the patient pathway between primary and specialized care.

*Abstract 2: Plan of radiotherapy's expansion in the unified health system of Brazil*

*Reinhard Braun and Leandro M Barreto, Instituto Nacional de Câncer, Rio de Janeiro, RJ, Brazil*

Brazil has a population of 197 million of people (IBGE Census, 2010). As in other countries, cancer is a public health problem, being responsible for 17% of known deaths and the second cause of death in Brazil. The estimates of new cancer cases are about 0.5 million per year (INCA, 2012),

including non-melanoma cancer.

There are 277 cancer centres (124 with radiotherapy treatment) providing public services for the population. These centres comprise public and private (philanthropic) providers and represent approximately 60% of the total capacity available for cancer treatment in Brazil.

In 2011, the National Institute of Cancer (INCA), a governmental arm of Ministry of Health, studied deficiencies of public services for cancer treatment, including coverage of public radiotherapy services and quantity, localization and obsolescence of radiotherapy equipment.

These studies were used to identify the necessity for new facilities and linear accelerators (Linacs) and the necessity for replacement of obsolescent equipment (Linac and Cobalt). The studies defined a deficit of 94 new Linacs by 2015 and a total deficit of 286 Linacs through 2023.

Based on this scenario, the Ministry of Health, supported by INCA, launched an ambitious public plan for investment, forecasting the implementation of 80 new radiotherapy units in oncology centres, improving radiotherapy centres whenever possible and creating new radiotherapy services in other oncology centres.

This analysis also takes into account the need of specialized human resources in the area. This plan includes an investment of more than R\$ 500 million (approx. US\$ 250 million), including the construction of new facilities, brachytherapy and radiotherapy equipment, including technology transfer to Brazil by 2015.

*Abstract 3: Oncology patients' treatment delay up to 2012 and current service improvement from January 2013 at Tikur Anbessa Hospital Radiotherapy Center*

*Mesfin Anley, Radiotherapy Center, Tikur Anbessa Hospital, Addis Ababa, Ethiopia. Tikur Anbessa Hospital in Addis Ababa is the only centre for cancer chemotherapy and radiation therapy in Ethiopia (population 90 million)*

Patients are referred from nine regions and two administrative cities of the country. Significant numbers are transferred from the main hospitals of different regions. Some patients also come from neighboring countries such as Djibouti and Somalia. The numbers of patients increases exponentially by 14% per year.

Referred and transferred patients do not have the opportunity to get treatment as soon as they arrive. They are evaluated by centre physicians; with work up and treatment decision by oncologists. Delays of weeks, even months, arise because of long waiting lists for each step to get treatment. In addition, after delays to get chemotherapy, delays of three

months for radiation therapy may be expected.

Limited resources, few oncologists with different responsibilities and high clinical service demands, limited accessibility to specialists, shortage of trained staff nurses, inadequate space for in- and out-patient management and limited accessibility, affordability and availability of cytotoxic drugs are serious challenges to the timely delivery of appropriate chemotherapy and cancer treatments.

The challenges for health professionals to handle this clinical practice burden are:

- Consoling patients for long delays in their expectation for treatment.
- Limited, trained manpower capacity to satisfy treatment needs.
- A frustrating/distressing workplace, particularly for nurses (e.g., communicating badly while calling patients for possible chemotherapy or radiation treatment).

Service improvements in 2013 between January and June, included:

- The introduction of a special room for day care with 10 beds for chemotherapy and blood transfusion.
- A new isolation room for chemotherapy preparation.
- An additional examination room established.
- An increased number of physicians and nurses employed.
- Coordination of utilization and scheduling of radiation units.
- Addition of a new practice-training radiographer.

#### Box 3: Recommendations from Workshop 3

- Enhance professional training and encouragement of community medicine
- Reinforce the role of cancer registries to set priorities
- Establish priorities for access and treatment according to local realities
- Implement customized protocols for treatment and follow-up

## 4. Mobilizing communities

*Margaret I Fitch, International Society of Nursing in Cancer Care, Canada, and Tatiana Vidaurre Rojas, Instituto Nacional de Enfermedades Neoplásicas (INEN), Peru*

Influencing change in cancer control can be effectively achieved through the efforts of mobilized communities. Networks, coalitions, and communities of practice are useful vehicles to increase awareness, provide education and training, offer support and guidance, and enact leadership for improving access to treatment and care for cancer patients and their families. However, it takes intentional effort to mobilize a community and to have its efforts

directed effectively. The health care system itself is complex; but effective change requires efforts beyond those of the health care sector. Political commitment and the efforts of sectors such as education and public policy are necessary.

This workshop was designed to:

- ▶ Explore how to leverage the opportunities of collaboration to build supportive networks; strengthen advocacy efforts and reinforce efforts on education, training, mentorship and leadership.
- ▶ Discuss who the leaders are and how to equip them for tomorrow's health care. Collaboration is working with another person or group in order to achieve or do something. Through collaborative efforts, expertise and resources can be leveraged to achieve desired outcomes beyond what one organization can achieve working alone.

Leaders working within and through collaborative efforts in this complex environment must be skilled in facilitative leadership and transformational change.

The abstracts selected for presentation during this workshop illustrate models of collaboration and describe strategies used to mobilize efforts in cancer education of health care providers and support for patients.

*Abstract 1: Impact assessment of the Early Diagnosis Programme: Does building capacity of primary health care workers have an impact on referrals for suspected paediatric cancer?*

*Viviane S Junqueira, Instituto Ronald McDonald, Rio de Janeiro, RJ, Brazil; Carmem Maria C Fiori, Universidade Estadual do Oeste do Paraná, Cascavel, PR, Brazil; Cynthia Magluta, Instituto Fernandes Figueira, Rio de Janeiro, RJ, Brazil and Ana Maria M Costa, Instituto Fernandes Figueira, Rio de Janeiro, RJ, Brazil and União Oeste Paranaense de Estudo e Combate ao Cancer, Cascavel, PR, Brazil*

#### *Introduction*

In Brazil, the time between symptoms and diagnosis (lag time) for paediatric cancer is long and many patients are referred to treatment with advanced disease. NGO Instituto Ronald McDonald (IRM) developed the Early Diagnosis Programme (EDP) to build capacity of primary health care workers and improve patient care flow from primary care to treatment hospitals. Since 2008, the programme has been operational in 86 cities in 12 Brazilian states, providing training for 14,553 health professionals.

#### *Objective*

To evaluate the adequacy and impact of the EDP.

#### *Method*

A longitudinal retrospective multicentre study, involving nine referral hospitals, based upon a comparison before and after the 2010 intervention, stratified by regions which had or had not received the EDP. Adequacy indicators were used in the capacity-building training and availability of EDP materials; impact indicators were the number of children referred for suspected cancer and the lag time. Data were collected from medical records, interviews (with nurses and patient families) and the EDP database.

#### *Results*

Of the physicians and nurses registered in the programme in 2010 (n=621), 80% achieved the expected attendance rate (75%) and 54% reported use of EDP material in their practice. A total of 1,797 medical records were analysed. A before and after comparative assessment showed a 23% rise in the number of children referred. The median lag time fell by 61% in the regions operating the EDP (from 13 to five weeks).

#### *Conclusion*

The programme was carried out as anticipated, and the targets were achieved. The impact can be inferred from the increased number of referrals for suspected paediatric cancer and the reduced lag time. No other factors that could explain this result were identified.

*Abstract 2: The Rare Disease Movement: The importance of collaboration between academia and civil society*

*Piga R Fernandez, Alianza GIST/Life Raft Group, Santiago, Chile*

Alianza GIST (AG), a coalition of advocates from 14 Latin American (LA) countries, was formed in 2009 to improve the survival of people living with a rare cancer called GIST (Gastrointestinal Stromal Tumour), through scientific research, information, education and advocacy.

As with many rare diseases, GIST is often misdiagnosed (AG has seen up to 20% misdiagnosed cases). One of the main goals of AG is to focus on educating the medical community about timely and proper diagnosis. AG has partnered with its member Fundacion GIST Mexico, the Life Raft Group (an international GIST advocacy organization) and the Instituto Tecnológico de Monterrey (a prestigious academic institution), using an intersectoral approach to change physician behaviour. Launched at ASCO 2011, the first GIST online CME course was introduced to LA physicians in conjunction with the first LA GIST Joint Tumor Board, in which a thoughtful discussion took place on how to resolve issues of misdiagnosis reaching regional and global

dimensions. The GIST online course has also been presented to medical students, interns, and physicians who see GIST patients across LA, to teach them basic knowledge about the diagnosis, treatment and management of GIST. AG representatives have promoted the course to the medical community in each of their countries with good reception.

This joint collaboration is an important start to closing the information gap in the medical community and increasing the index of suspicion among those that see GIST patients. It establishes a precedent for an integrative, interdisciplinary approach to solve an uncommon population health problem.

**Abstract 3: Peruvian Breast Cancer Club: A big issue for health promotion. Volunteer Survivors Breast Cancer Club Programme at the Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru**

*Susana Wong, Club de la Mama, Lima, Peru; Shirley Quintana, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru; Jeannie Navarro, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru; Gabriela Calderon Valencia, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru; Abel Limache-Garcia, Comisión de Lucha Antitabaquica-Coalición Multisectorial Peru contra el Cáncer, Lima, Peru; Miguel Ruiz-Ninapaytan, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru; Fanny Romero, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru and Tatiana Vidaurre Rojas, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru*

#### Background

In Peru, adequate measures to control and prevent cancer are necessary, not only by preventing exposure to risk factors, but also by the acquisition of a healthy lifestyle and provision of integrated support for patients with a diagnosis of cancer.

#### Methods

Efforts were focused on breast cancer patients who often present emotional and social challenges. One-to-one peer survivor counselling to provide hope and optimism through emotional support and guidance through treatment is essential for optimal care. The Breast Cancer Club is a group of volunteer breast cancer survivors who provide peer support based upon their own cancer experiences.

#### Results

This programme has improved the resilience and ability to cope with cancer. Since 2006 volunteers (survivors) provide counselling through use of personal experience, skills, and

behaviours that enhance effective support. Outreach and screening methods targeting specific breast cancer groups have been developed, increasing the number of patients receiving culturally-appropriate awareness and support. The benefits to providers include improved participation, more effective engagement for better compliance with treatment and increased patient satisfaction.

#### Conclusions

Models such the INEN Breast Cancer Club Programme provide a very useful health practice in developing countries. The inclusion of volunteers in the Breast Cancer Club requires more work and understanding to ensure sustainability within leadership and management. Initial experience demonstrates that the implementation of such programmes in a major cancer centre is feasible, acceptable and beneficial for increasing survival and quality of life for persons with cancer.

#### Box 4: Recommendations from Workshop 4

- Making use of networks is important in mobilizing a community to action
- It is vital to listen to the community, understand its views and needs; institutions need to partner with the community (engage, work together) through collaborative alliances
- Network membership should comprise those who can enact mutually-agreed solutions
- Engage and empower existing groups and local leaders within the community
- Build upon existing strengths of partners – add new partners as appropriate (inclusivity)
- Empower local leaders and leverage their influence, knowledge and credibility to enact cultural and political change
- Use clear simple messages communicated through a variety of media

#### Discussion and conclusion

*Rolando Camacho, Program of Action for Cancer Therapy, International Atomic Energy Agency, Vienna, Austria, and Claudia Naylor, Instituto Nacional de Cancer, Brazil*

Current strategies to control cancer are demonstrably deficient. In India the death toll from cancer, one of the world's leading causes of death, has risen by almost 40% since 1990 and will continue to do so (1,15). New directions are necessary.

Health systems can affect cancer outcomes through prevention, early detection, effective treatment and palliation enabled by universal health coverage, innovation,

safe high-quality care and informed social policy.

Prevention will always be preferable to care in diseases with high morbidity and mortality, but preventable cancers are not being presented. Patients suffer and die needlessly from cancers that are boasted equitable and curable and new curative therapies have limited accessibility, applicability and affordability. If complemented by effective early detection and treatment, primary prevention is a highly effective approach to cancer control; however, the benefits take time to manifest and need sustained leadership and vision from policy-makers. Individualized approaches to control incidents are less likely and less cost-effective than the sociopolitical actions through policy, legislation and regulation, and do not require renewal with each generation (6,9,10,11,19).

Population-based registries for collection, management and analysis of cancer data are of fundamental importance to all countries. Synthesized data contributes to effective, efficient and sustainable cancer systems, allowing “all of society” to participate by building a clear picture of need, capacity and effectiveness of interventions (3,11, Session 3: ICC-5).

Expanding cancer control within the context of universal health insurance, using priority disease-specific interventions to drive improvements in health systems, can expand coverage and improve access across diseases and populations. Integrated strategies that cross disease-specific and system-wide constraints (e.g., tobacco control and NCDs); physical activity and healthy nutrition; empowering women through better knowledge about breast cancer; and strengthened health systems to support better access to pain control overcome the limitations of “vertical” or “horizontal” initiatives (9,10,14). Brazil, Colombia, Costa Rica, Cuba, Dominican Republic, Mexico, Panama and Peru have included cancer care and control in their national insurance programmes. Universal health care “Seguro Popular” (Mexico) offers universal health care coverage,

covering treatment for cancer in children, breast and several other cancers (2,9) with early indications of increased participation and decreased abandonment of treatment (8).

Increased access to primary care with well-designed and affordable disease control programmes offers opportunities to enhance cancer control. Upgrading the role of communities, ensuring continuity of care across general and specialized environments, integrating primary and specialized care, evidence-based guidelines and care paths and innovative approaches to access to therapies is all particularly important for LMICs. For several cancers, life can be extended with fairly low-cost systemic therapy and palliation for pain relief is an essential human right for which the barriers of substance control and prejudice of policy-makers are unacceptable (7-13).

A global call to action for cancer in LMICs is beginning to emerge. Partnerships between governments, NGOs, transnational agencies, medical institutions, private sector, health professionals and the patients and public working through evidence-informed policies and best practices from all jurisdictions will be required to achieve the necessary level of response for the global cancer challenge.

#### *Acknowledgments*

*This manuscript is a synthesis of plenary presentations, workshop discussions, including selected abstract presentations, and recommendations for ongoing actions derived from Session 4 of the Fifth International Cancer Control Congress (ICCC-5) held in Lima, Peru, 3-6 November 2013. The ICC-5 working group was made up of Simon B Sutcliffe, Kavita Sarwal and Catherine G Sutcliffe from the International Cancer Control Association, Tatiana Vidaurre Rojas and Roxana Regalado from the National Cancer Institute (INEN) in Peru. The opinions expressed herein represent those of the authors alone and do not necessarily represent the institutions and organizations by which they are employed.*

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# THE FIFTH INTERNATIONAL CANCER CONTROL CONGRESS

## SESSION 5: INTEGRATING RESEARCH, PRACTICE AND POLICY PRIORITIES TO IMPROVE CANCER CONTROL

# SESSION 5: INTEGRATING RESEARCH, PRACTICE AND POLICY PRIORITIES TO IMPROVE CANCER CONTROL

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Improving cancer control outcomes is a complex process that requires integrating research with both practice and policy priorities at the national, regional and local levels. It requires data from surveillance systems to set priorities and track progress, appropriate and standardized metrics to measure progress, and pragmatic research to identify evidence-based interventions that can be translated into practice and policies adapted to the local context. Dissemination and implementation research further facilitates the integration of research with practice and policies by studying the processes for integrating the lessons learned from science with the lessons learned from practice and policy.

Session 5 of the Fifth International Cancer Control Congress (ICCC-5) focused on integration of research, practice and policy priorities to improve cancer control at a population level, through three plenary presentations and five interactive workshops:

1. Operations research in cancer control.
2. Research, practice, policy partnership models.
3. Moving from evidence to practice: The case of the Women's Cancer Initiative.
4. Implementation science and health economics in the context of cancer control.
5. How to take advantage of NIH implementation science funding opportunities to rigorously evaluate the implementation of cancer control programmes in Latin American, African or Asian countries.

Key issues raised included: the importance of practical measures, including health economics, that can show progress towards short-term goals for gaining support for cancer programmes and policies; the need to develop the field of health economics in Latin America and other LMICs; the need to ensure input from relevant stakeholders in pragmatic research so that findings are relevant to the needs and challenges of specific populations or settings; the need to understand the processes of how evidence-based interventions are successfully implemented through communities of practice that include researchers, practitioners and policy-makers; and finally the need for more funding and greater government support for cancer control research.

*Key words: Cancer control, pragmatic research, operations research, implementation science, health economics, Women's Cancer Initiative*

## Introduction

*Cynthia Vinson, Implementation Science Team, Division of Cancer Control and Population Sciences, National Cancer Institute (NCI), Bethesda, USA, and Luiz Santini, Instituto Nacional de Câncer (INCA), Rio de Janeiro, Brazil*

Improving cancer control outcomes is a complex process that requires integrating research with both practice and policy priorities at the national, regional and local levels. The “Evidence Integration Triangle” proposed by Glasgow and colleagues is helpful in conceptualizing such an approach (1). This model focuses across three areas:

- ▶ Developing and implementing practical measures for setting priorities and tracking progress of cancer control plans and programmes.
- ▶ Identifying appropriate evidence-based interventions and policies.
- ▶ Understanding the processes for successfully implementing evidence-based interventions.

Cancer control planners and decision-makers rely on data as a basis for setting priorities and tracking progress but the quality of data systems vary. Standardized surveillance systems for collecting and reporting incidence and mortality data are critical for cancer control planning. Most high-income countries (HICs) have these surveillance systems and many low- and middle-income countries (LMICs) have set the development and/or improvement of registry systems as a goal in their national cancer control plans. However, in addition to the standard surveillance systems, practical measures that are brief, easy to collect over time and sensitive enough to assess change in a short period are necessary. To help inform policy-makers, the measures should have national norms, be easily understandable and actionable (2).

In addition to quality data, a significant challenge exists in identifying appropriate evidence-based programmes and policies that can translate into practice. Traditional research studies rely on randomized control designs that test the efficacy or effectiveness of an intervention; however, while important, the traditional randomized study design limits generalizability. The majority of programmes and policies tested in a research setting do not readily translate into real world settings and those that do take a very long time to do so (3). For research to influence practice and policy, understanding context concerning implementation is fundamental. This can be a challenge since context can vary and occurs at many levels (e.g., organizational, local, community, regional, national) and is influenced by many

factors (e.g., political, environmental, economic). Pragmatic research that incorporates contextual, real-world factors is gaining support as a method for more rapid integration of research into practice and policy. Pragmatic trials include practitioners and decision-makers in developing the research questions so that the results can help answer questions that are most relevant to them and are more likely to translate into practice and policy solutions (4).

Dissemination and implementation research further facilitates the integration of research with practice and policies by studying the processes for moving research into practice and policy change. This includes studying strategies that effectively, equitably and efficiently implement health policies and guidelines as well as evaluating policy and other contextual factors that influence successful implementation or dissemination efforts. Moving research into practice requires an understanding of issues and barriers at a local level, which requires stakeholder engagement and community-based participatory research approaches.

## Methodology and objectives

ICCC-5 Session 5 on “Integrating research, practice and policy priorities to improve cancer control” comprised three plenary presentations to provide an overview of the subject matter as a means of preparing congress participants for participating in five, small group, interactive workshops on relevant topics to be addressed in greater depth. Selected abstracts providing particular insights into the topic area were presented orally by the authors in each of the workshops. Workshop leaders were encouraged to conclude their workshops with a brief set of prioritized recommendations to identify the key directions for further development of interventional activities beyond this congress.

The objective of this session was to discuss integration of research, practice and policy priorities to improve cancer control at a population level. The following five issues were selected for in-depth discussion in the workshops:

- ▶ Operations research in cancer control.
- ▶ Research, practice, policy partnership models.
- ▶ Moving from evidence to practice: The case of the Women’s Cancer Initiative.
- ▶ Implementation science and health economics in the context of cancer control.
- ▶ How to take advantage of NIH implementation science funding opportunities to rigorously evaluate the implementation of cancer control programmes in Latin American, African or Asian countries.

## Plenary presentations

### 1. Opportunities for integrating pragmatic research approaches to support practice and policy priorities

*Jon F Kerner, Canadian Partnership Against Cancer, Toronto, Canada*

In this plenary presentation, the question “if research evidence is to influence practice and policy then how must practice and policy priorities and conundrums also influence research questions and study designs?”(5) was addressed. Critical to making research-based evidence relevant to practice and policy knowledge users, is how research methods can integrate national, regional and community contexts into study designs so that the external validity of study findings is given as a high a priority by scientists proposing and reviewing studies for funding or publication as are the internal validity of the findings. Research resource information from the region was examined with respect to regional cancer control priorities, and international research, practice, and policy partnership models were discussed.

### 2. How is policy influenced beyond the health perspective?

*Eva Maria Ruiz de Castilla Yabar, Esperanza, Lima, Peru*

This presentation focused on the challenges and opportunities in Latin America around the practical application of health economics and discussed the broader context of policy planning in the region as it relates to plans for cancer control. One particularly important hurdle in Peru and elsewhere for the application of health economics is the availability, generation, and use of health data. Peru’s Plan Esperanza is an opportunity to reverse-engineer a policy programme to build a more comprehensive package of interventions for cancer control nationally.

The limited role and inconsistent application of health economics in health decision-making in Latin America and examples of growing trends in research, practice and policy knowledge exchange opportunities being supported by countries were discussed. For example, the application of health services research to cancer in Peru and the growing capability in the region to perform health technology assessment and expansion of universal health coverage were discussed. The region faces many challenges due to a lack of specialists in health economics, and a deficit in data to facilitate evidence-based decision-making. There are, however, examples of successful models, including Chile and Brazil, for research, practice and policy partnerships that could possibly be translated to other countries within the region. In conclusion, the need to cultivate the specialty of

health economics for the continued improvement of our health systems depends on this kind of expertise. Finally, all of these approaches are applicable more broadly than cancer, and are big ideas that are no longer debatable. Most importantly, cancer control planning must become an annual activity so that new ideas and evidence can foster new programmes for investment.

### 3. Integration of methodology of research on improvement of clinical practice

*Henry Gomez, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru*

Clinical research influences daily practice and supports the implementation of improvements in the management of patients. Translating scientific results into clinical practice leads to the adoption of well-designed, evidence-based strategies for patient diagnosis, treatment and follow-up. Scientific rigour, respect for the patients’ rights, adoption of good clinical practices, analysis of results and the results themselves can be immediately incorporated into daily practice.

However, incorporation of trial results into practice engages procedural, structural and infrastructural challenges that add complexity to patient diagnosis, treatment and follow-up (6). Overcoming these barriers to improve patient management requires strategic patient, professional and health system engagement in practice and policy change,

Supervision and follow-up of patients is essential to establish critical points, timing analysis, time windows and contingency plans within the overall care plan. Today, well-informed patients are very much engaged in their therapeutic decisions. Oncologist involvement in clinical research establishes the awareness, knowledge, confidence and trust to present options and alternatives within the decision process.

In conclusion, optimal patient care requires incorporation of research findings into clinical practice through harmonized patient, professional and health system policy.

## Workshops

### 1. Operations research in cancer control

*Rami Rahal, Canadian Partnership Against Cancer (CPAC), Toronto, Canada*

Meaningful and reliable measures of performance are a critical tool in the efforts to improve the quality of health care systems. In cancer control, where a broad range of strategies are employed to reduce the burden of cancer on

the population, from prevention and screening, to diagnosis and treatment, to supportive and end-of-life care, performance indicators can help shed light on where the biggest opportunities for improvement are. Performance measurement at a system level requires routine collection of valid and reliable data, which in turn requires sophisticated standardized data collection and repository infrastructure. This is often a challenge, particularly for countries with rudimentary registries and very little in the way of data on interventions and patient outcomes.

This workshop explored how quantitative and qualitative approaches can be used for measuring and evaluating the cancer control system in three different settings: a targets monitoring effort at the international level, a comprehensive national system performance reporting system in a HIC, and foundational measurement and reporting in a LMIC. The first abstract presented a framework to measure and monitor countries' progress towards achieving the World Cancer Declaration targets. The second abstract outlined the development of a national cancer control system performance programme in Canada and presented examples of indicator results and how they are used to set targets. The third abstract provided the early results of efforts to measure service utilization in Peru using the local insurance database.

Workshop discussions were based on participants' experience to answer the following questions:

- ▶ How do you get to the stage where you can collect and report on useful data for measurement and evaluation in a system with poor data resources and/or disparate data standards?
- ▶ In your country, what has been the response to efforts to measure and evaluate progress towards achieving cancer control objectives?
- ▶ In your experience, what strategies have proven successful in facilitating acceptance and uptake of performance measures and targets by clinicians, administrators and policy-makers?

*Abstract 1: Creating a framework to measure progress in global cancer control: Benchmarking against the World Cancer Declaration targets*

*Rebekkah Schear and Stephanie Nutt, LIVESTRONG Foundation, Austin, TX, USA*

#### *Objective*

To conduct an assessment of international cancer control efforts benchmarked against the 11 World Cancer Declaration 2020 targets.

#### *Background*

Data collected from a 2007–2008 study illustrated that the global cancer community lacked the capacity to galvanize around key cancer issues. In 2009, a formal call for commitments was launched, aligning with the World Cancer Declaration targets and modelled on the Clinton Global Initiative commitment process. Between March–July 2009, 350 commitments from advocates, NGOs, corporations, world leaders and health care practitioners in 68 countries were submitted. In August 2009, stakeholders were convened for advocacy and programmatic capacity-building.

#### *Methods*

In 2010–2011, two rounds of self-reported data collection were conducted through an online survey assessing progress against the World Cancer Declaration targets in specific categories including people trained, programmes created, people reached, partnerships created, new/changed policies, research projects established, dollars raised and dollars awarded.

#### *Results*

One hundred and sixty-seven completed follow-up surveys from 134 unique organizations and health care practitioners were submitted. Results indicate that stakeholders directly affected 5,056,652 lives through services and interventions and indirectly affected 246,835,971 lives through education and awareness efforts.

#### *Conclusion*

Significant progress is being made towards achievement of the World Cancer Declaration targets, specifically towards target one (creation of sustainable delivery systems), target five (improving public attitudes and dispelling myths), target six (improvements in detection) and target 11 (improvements in survival rates). However, capacity-building in monitoring and evaluation for NGOs and creation and collective use of a more standardized measurement framework are critical to reflect the continued evolution and growth of global cancer control.

#### *Implications*

It is increasingly important for civil society organizations to assist national cancer programmes, particularly as government leaders are called to meet new global goals for NCDs. Progress on the Global Monitoring Framework on NCDs will need to be measured and this data provides a model for such measurement.

*Abstract 2: System performance measurement and target setting in the Canadian cancer control system – a five-year journey of building indicators and trust*

*Rami Rahal, Canadian Partnership Against Cancer, Toronto, ON, Canada*

While most cancer control jurisdictions in developed countries and many in developing countries regularly collect and report standard surveillance data (such as incidence and mortality rates) there are very few examples of comprehensive system performance efforts that provide country-level data across the continuum from prevention and screening, through diagnosis and treatment, to survivorship and end-of-life care. One of the key barriers to reaching this goal has been the challenge of building comprehensive administrative data collection and repository systems. While this may seem a daunting task in many places, the Canadian experience suggests substantial progress can be made over a relatively short time period given a focused effort and a collaborative approach.

Over the last five years, the Canadian Partnership Against Cancer's (CPAC) System Performance initiative has worked in partnership with provincial cancer programmes to systematically build a national programme for reporting cancer control indicators. The work started in 2008 with very little in the way of standardized country level data beyond registry-based surveillance metrics and some wait times data. The first system performance report published in 2009 provided data on 17 indicators but kept the provinces anonymous. The report was not positioned as a report card but rather a resource for identifying best practices and opportunities for improvement. This positioning, along with the deliberate collaborative model, helped cultivate trust in the process among the provincial cancer authorities, which led to the 2010 report openly identifying provinces and also adding indicators on diagnosis and treatment practice. The 2011 report then moved to measuring interprovincial variations in concordance with evidence-based guidelines. By 2012, the provinces were asking for targets and benchmarks to be added and for measurement to be expanded to new domains including patient safety and system efficiency. This progressive building of trust in the process was accompanied by increased proficiency in data management and indicator development leading to progressively more sophisticated metrics and analyses planned for the 2013 and 2014 reports.

The presentation outlined the Canadian system performance journey from modest data capabilities and limited experience in interprovincial collaboration on

performance measurement among provinces to the sophisticated knowledge products and processes we have today. Results from a number of key indicators were also shared along with work underway to develop performance targets and quality improvement initiatives.

*Abstract 3: Comprehensive health insurance at INEN: First four-month period of 2013*

*Marga E Lòpez Contreras, Department of Patient Care Services, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru; Ebert Poquioma, Department of Epidemiology and Statistics, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru; Mariela Pow Sang, Division of Support Services for the Diagnosis and Treatment, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru; Luz Loo, Insurance Office, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru and Doris Cárdenas, Institutional Vice-Chief, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru*

*Objective*

To review the medical care (outpatient care, hospitalization, surgery, chemotherapy and radiation therapy) provided to patients through Comprehensive Health Insurance (CHI) in the first four months of 2013.

*Results*

A total of 29,566 patients received care in this period, of which 16,189 (54.8%) were CHI patients. In this group 3,370 (20.8%) cases were diagnosed in 2013, 4,595 (28.4%) in 2012, and 8,224 (50.8%) in previous years.

During the study period, 2,355 surgeries were performed, including 1,765 (75.0%) in the CHI group. Of these surgical procedures, 43.3% were for high-cost diseases, including breast, cervical, stomach and colorectal cancers.

During the study period, 4,012 patients were discharged from the hospital, including 2,959 CHI patients (73.8%), of which 53.7% were from high-cost diseases, e.g., leukemias, breast and cervical cancers.

There were 90,193 clinical consults, of which 69.7% (62,859) were CHI patients. Breast, cervical, stomach cancer, leukemias and lymphomas were the leading diagnoses.

Radiation therapy facilities were used by 83.3% of CHI patients in this period. Cervical and breast cancers were the most common cancer types, with other frequent sites being lymphomas and prostate cancer.

Outpatient chemotherapy facilities (children and adults) were used by 16,475 patients; 88.5% were in the CHI population. Leukemias and breast cancer were the leading cancer types requiring chemotherapy.

**Box 1: Summary of Workshop 1**

- ▶ Measurement and reporting in data-poor systems requires training, centralized information systems and collaboration with clinicians and other users
- ▶ Targets are useful when there is baseline data, they are feasible, set at multiple levels of administration and geography and based on evidence and expert input
- ▶ Increased data/indicator use can be achieved by ensuring data is high quality, includes fundamental metrics and allows for empowerment of users

**2. Research, practice and policy partnership models**

*Jon F Kerner, Canadian Partnership Against Cancer (CPAC), Toronto, Canada*

While enormous amounts of new cancer control knowledge have been generated worldwide, driven in large part by public sector and some private sector research investments from HICs, relatively little has been invested to translate the lessons learned from science into policy and practice (7). The slow uptake of evidence-based intervention approaches in HICs has been recognized as dissemination and implementation or knowledge translation and exchange challenges. While a growing recognition of these challenges has taken hold in HICs (8–11) the challenges in LMICs are even more complex.

In LMICs, many of the research findings emerging from HICs may often be viewed as context irrelevant (12), and the public resources for supporting context-specific research are much more limited. Private sector research funding often is the dominant player in LMICs, and these funds tend to focus on clinical research questions rather than broader cancer control practice and policy questions (13).

For both HICS and LMICs growing repositories of research (e.g., PubMed) combined with modern communication technologies (e.g., the internet) means that an enormous amount of research information is available seven days a week and 24 hours per day. An unintended consequence of this may be a signal to noise ratio problem with too much information being processed with too little time to contextualize the information into practical knowledge.

One solution to all these challenges is the development of research, practice and policy partnerships (14) that help provide a context by which research findings can be interpreted by knowledge users both for translating the lessons learned from science into practice and to identify practice and policy questions that have not been addressed by the research enterprise and where answers are often

urgently needed by practice and policy specialists (15). Research, practice and policy models were reviewed in this workshop.

*Abstract 1: A new paradigm of cancer control for adolescents and young adults (AYA): A framework for action from the Canadian Task Force for AYA with Cancer*

*PC Rogers, BC Children's Hospital, Vancouver, BC, Canada; RD Barr, McMaster University, Hamilton, ON, Canada; B Schacter, CancerCare Manitoba, Winnipeg, MB, Canada and S De Pauw, McMaster University, Hamilton, ON, Canada*

**Background**

The objective of the National Task Force (NTF) is to enhance the care of AYA with cancer in Canada. Multidisciplinary clinical programmes staffed by trained health care professionals, a systems improvement approach, continuous engagement of all stakeholders and ongoing evaluation and research are all required. The NTF was established in 2008 with the support of the Canadian Partnership Against Cancer and C17 (the consortium of all paediatric oncology programmes in Canada).

**Process**

A developmental approach, combined with disease-specific clinical expertise, is fundamental to achieving the maximal survival benefits, the greatest impact on quality of life and the optimal functioning and productivity of survivors. Two international workshops were held, attended by health care professionals, survivors, administrators, researchers and international experts. The first workshop (March 2010) produced specific recommendations (16). The second workshop (March 2012) produced a framework for action to implement those recommendations (17). These included establishment of regional action partnerships to improve active treatment, increased accrual to clinical trials, development of guidelines for active care and long-term follow-up, and provision of age-specific psychosocial supports. Other initiatives include development of an evaluation process including economic metrics, the creation of an AYA cancer diploma programme administered by the Royal College of Physicians and Surgeons of Canada, a programme of collaborative AYA research and a knowledge translation and exchange strategy. The NTF continues communicating and working with all stakeholders to activate its recommendations and action plan.

**Conclusion**

This inclusive process will influence and improve the cancer

control paradigm for AYA with cancer and AYA survivors of cancer in childhood, adolescence and young adult life in Canada.

*Abstract 2: Coalitions Linking Action and Science for Prevention (CLASP): A research, practice, policy partnership model*

*Deb Keen, Kristin D Honshorst and Jon F Kerner, Canadian Partnership Against Cancer, Toronto, ON, Canada*

CLASP is a funding initiative of the Canadian Partnership Against Cancer that brings together organizations across two or more provinces and/or territories and research, practice and policy experts to work together to broaden the reach and deepen the impact of evidence-informed interventions for cancer and chronic disease prevention.

The seven projects funded in 2009 for three years involved over 1,100 individuals and organizations, including 53 research, 232 practice and 119 policy experts, with other non-health sectors. The project interventions impacted over 142,000 individuals and organizations across every province and territory in Canada.

The 172 interventions implemented by the seven projects aimed to change or improve environments, change individual behaviours, influence policy, legislation or regulations and influence provision of health or social services.

Project impact included results such as:

- ▶ Municipal planning software developed in British Columbia that demonstrated how built environment planning would lead to an 86% increase in active trips/person/day, 102% increase in cycling to work/school and 10% increase in daily energy expenditure.
- ▶ Implementation of a SipSmart! school curriculum in the Northwest Territories resulted in a student-reported 8% decrease in the consumption of sugar-sweetened beverages after completing the programme.
- ▶ Family practices with a prevention facilitator delivering patient-level prevention and screening interventions in Alberta and Ontario accomplished a statistically significant increase (approximately 2.5 times) in their eligible screening and prevention targets compared to control practices not participating in the intervention.

Cross-CLASP evaluations of 124 coalition members indicated a statistically significant transition within coalitions from networking and coordination to cooperating and collaborating.

The CLASP coalition model has been able to leverage what

is working in one province or territory and transfer it to others. CLASP continues as a CPAC funding initiative with additional projects recently funded for a three year implementation period.

*Abstract 3: Generation collaborative research groups within cancer research priorities for cancer control*

*Abel Limache-García, Tatiana Vidaurre Rojas, Cesar Samanez-Figari and Carlos Castañeda-Altamirano, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru*

*Background*

Current interventions for cancer control were generated according to scientific evidence for prevention, detection, diagnosis, treatment and palliative cancer care. However it is critical that scientific evidence be generated in a systematic, orderly way and in collaboration and coordination with collaborative research groups with more experience.

*Objective*

To facilitate the development and operation of collaborative research groups in the region of Latin America to set cancer research priorities.

*Methodology*

The process for identifying research priorities in oncology was through workshops with researchers and doctors to enable more efficient use of resources. Concurrently, INEN established partnerships with other regional cancer research institutes to implement and strengthen oncology research.

*Results and conclusions*

INEN has established strategic alliances with the National Institute of Health of Peru, the leading research institute in Peru, the National Cancer Institute (USA) and South West Oncology Group (SWOG), thereby allowing INEN to strengthen and develop cancer research priorities in Peru, including public policies, preventive vaccines, healthy lifestyles, diet, physical activity, infections, prevalence of modifiable risk factors, molecular epidemiology, environment and cancer, methods of early detection and timely diagnosis, molecular classification of patients to evaluate predictive factors for treatment, systemic treatment, surgical and radiation therapy, psychoemotional support, effective and innovative interventions for nursing care, pain management protocols, strategies for rehabilitation and social reintegration, cancer burden and innovation in the training of

professionals in oncology. The next step is more economic support through our cancer control and prevention planning.

**Abstract 4: Occupational and environmental cancer: An intersectoral national strategy to support surveillance**

*Ubirani B Otero, Márcia S Mello, Flávia N Carvalho, Vanessa Í da Costa, Fellipe O Pinto, Paula Gabriela S de Oliveira, Letícia V de Mesquita and Sheila O de Castro, Instituto Nacional de Enfermedades Neoplásicas (INEN), Brazil, Rio de Janeiro, RJ, Brazil*

**Introduction**

Some reports indicate that rates of occupational and environmental cancers are being underestimated, despite the 111 carcinogens known to be related to them. Registration and notification of cancer cases are hampered by long latency periods between exposure and disease, the difficulties in assessing exposure, low technical training for diagnosis and inattention to details of occupational exposure. Accurate determination of exposure risk, disease causality and implementation of an effective surveillance system are required to address occupational and environmental cancers.

**Objectives**

Present and discuss strategies used in successful national intersectoral actions for the investigation of carcinogenic agents.

**Methods**

Occupational and environmental risk factor investigation projects were carried out on populations exposed to carcinogens in three rural counties in southern Brazil (2007–2012). One proposal was to implement a pilot study in a tobacco-grower county to subsidize strategies linked to the Framework Convention on Tobacco Control. This work was implemented by the National Cancer Institute with the participation of sections of the Ministries of Health and Agrarian Development, as well as support from the State and Municipal Health Secretaries.

**Results**

This partnership project has been a successful experience. Each partner institution is fully aware of their role and of the precise time for their engagement. The flow begins with federal coordination and moves towards state and municipal levels, where the network of well-trained family health teams reaches the target population, captures information and performs the necessary interventions. Thereafter a

counter-flow is established ensuring the return of information and materials. At the end of the process, feedback of the results is given to the population by means of discussion forums and local surveillance strategies are adopted.

**Conclusion**

In a country with scarce health resources like Brazil, optimizing previously established health networks ensured the success of the investigation project and the implementation of a surveillance programme.

**Box 2: Summary of Workshop 2**

- ▶ Less dependence on corporate research funds and more strategic government funding for health research is required. This is predicated on:
  - research questions being partially defined by practice and policy priorities
  - forums for knowledge exchange between research, practice and policy experts being available, with researchers learning how to communicate with policy-makers
- ▶ To be relevant to local and regional priorities, research must be done in or with involvement of those jurisdictions
- ▶ National government practice resources and policy priorities must be translated into local and regional jurisdictional contexts to be relevant

**3. Moving from evidence to practice: The case of the Women's Cancer Initiative (WCI)**

*Silvana Luciani, Pan American Health Organization, Department of Noncommunicable Diseases and Mental Health, Washington, DC, and Javier Manrique-Hinojosa, Instituto Nacional de Enfermedades Neoplásicas (INEN), Lima, Peru*

Worldwide, breast and cervical cancer are the most common cancers among women, and the majority of these cancers are in LMICs (18). Recent research has defined the cause of cervical cancer and technologies have been developed for prevention, notably HPV vaccines, screening tests including HPV DNA tests, cervical cytology, visual inspection with acetic acid (VIA) and cryotherapy for treatment of precancerous lesions. Although less is known about breast cancer, ongoing research is contributing to the development of new treatments and to the evidence base for education and awareness, patient empowerment, clinical breast examination and mammography screening for early detection and improved patient outcomes. However, the application of this evidence and these technologies, especially in LMICs where the burden of disease is greatest, has not been as rapid or as

large-scale as needed to reduce mortality.

The WCI was created to spur international cooperation and partnerships within the Americas region, to support countries in Latin America and the Caribbean to accelerate the deployment of technologies and evidence for breast and cervical cancer prevention and control. The WCI, led by PAHO and involving over 20 partners from governments, nongovernmental organizations, academia and the private sector, offers a case example of how evidence can be promoted and new knowledge shared so that public health programmes can be improved by integrating evidence-based technologies.

Workshop presentations included Argentina's national cervical cancer programme, results of a review on the application of the Breast Health Global Initiative guidelines and the work of the Network of Cancer Institutes of South America (RINC). Enabling factors and barriers influencing the incorporation of new knowledge into public health policies and programmes for breast and cervical cancer prevention, screening and treatment and how the WCI can be leveraged to improve policies and programmes in their country were discussed.

**Abstract 1: The experience of the National Program on Cervical Cancer Prevention in Argentina: A comprehensive approach**

*Silvina Arrossi, CONICET/CEDES, Buenos Aires, Argentina, and Rosa Laudi, Ministerio de Salud, Buenos Aires, Argentina*

In Argentina, cervical cancer mortality has been largely unchanged for the last 30 years despite the availability of cervical screening for more than 50 years. The National Program on Cervical Cancer Prevention (NPCCP) was re-launched in 2008 with the objective of strengthening provincial programmes, achieving high screening/diagnosis/treatment coverage and developing an information/monitoring/evaluation system.

Agreements between national and provincial governments were signed in 10 provinces in order to get consensus about the political priority of cervical cancer prevention and to coordinate activities. Communication/information strategies were designed for women from different regions and social backgrounds. Special emphasis was put on working with health professionals and authorities to increase adherence to programme guidelines (i.e., age/interval of screening, laboratory centralization). Cytology laboratories were newly equipped and in-service training took place in 12 laboratories from eight provinces, involving more than 95 staff. A team of navigators provided support to women with precancerous lesions through the diagnosis/treatment process. SITAM

(Information and Monitoring System for Screening) was implemented to monitor/evaluate programme performance and is currently in use in 19 provinces.

In five provinces, main laboratories have doubled the number of read smears, decreased the percentage of unsatisfactory Paps and improved turnover-time. In 2011, the country initiated a demonstration project to introduce HPV-testing for primary screening as part of an integrated approach to prevent cervical cancer that also includes HPV-vaccination for girls beginning at 11 years of age. The goal is to HPV-screen 22,000 women annually over three years and reach 80% coverage. During 2012, 22,589 women aged 30+ were screened, with a positivity rate of 12.7%. Among those, 921 had an abnormal Pap smear. Based on these results, HPV testing is being extended to other provinces.

The NPCCP demonstrates the importance of an integrated approach to achieve an impact upon cervical cancer.

**Abstract 2: Use of the Breast Health Global Initiative (BHGI) Guidelines for breast cancer control in LMICs**

*Maria I Echavarría, University of Washington Department of Global Health, Seattle, WA, USA; Beti Thompson, Fred Hutchinson Cancer Research Center, Seattle, WA, USA and Benjamin O Anderson, Fred Hutchinson Cancer Research Center, Seattle, WA, USA*

Resource constraints in developing health systems require difficult allocation decisions to optimize cancer outcomes. Cancer care guidelines developed in high-income countries have limited utility in LMICs because many of the resources described in the ideal health care delivery system are unavailable or unaffordable, making it unclear where to begin in creating a realistic and sustainable cancer control strategy. New approaches to health care system design require that an evidence-based approach to resource prioritization be established.

The Breast Health Global Initiative (BHGI) held five Global Summits (2002, 2005, 2007, 2010 and 2012) to develop evidence-based, resource-stratified guidelines for LMICs. These guidelines address the areas of early detection, diagnosis and pathology, treatment and health care systems, as well as identifying effective implementation strategies and measures for success of such implementations. Bringing together experts from around the world to discuss and reach consensus on breast cancer care and management, these guidelines have been published in a series of journals since the first summit was held. The purpose of this report was to evaluate the degree of attention that has been placed on the BHGI Breast

Cancer Guidelines in the published literature since its first publication by:

- ▶ Documenting how many times each BHGI guideline has been cited (to assess the impact of the guidelines).
- ▶ Identifying the application of each guideline in terms of where (regions or countries) and when (year of citation after the publication of the guideline) the citation occurred.
- ▶ Ascertaining the purpose of the use of the guideline in the corresponding article in which it was referenced.
- ▶ Evaluating trends in citation among the different guidelines, to understand what information has been more relevant for limited-resource countries.

*Abstract 3: Scaling-up commitments to meet the challenges in regional South-South collaboration – a regional network of national cancer institutes prioritizes cervical cancer control, builds consensus and endorses best practices*

*Walter P Zoss, Red de Institutos Nacionales de Cáncer (RINC/UNASUR)/ INCA Brasil, Rio de Janeiro, RJ, Brazil, and Leigh Passman, Instituto Nacional de Câncer, Rio de Janeiro, RJ, Brazil*

Cervical cancer is the second most common cancer among women in Latin America, ranking first in some countries, with about 68,220 new cases and 31,712 deaths.

Despite many initiatives in Latin America against cervical cancer and the introduction of early detection programmes, mortality rates from cervical cancer have not declined. Barriers to participation in cervical cancer screening vary in different countries.

The Network of National Cancer Institutes (RINC), organized under the auspices of the Union of South American Nations (UNASUR) seeks to align public cancer prevention and control recommendations and policies and share programme experiences that have been successful and that might be adapted and implemented by other network members. RINC member institutions are working together to address a number of challenges in cancer prevention and control, but have prioritized cervical cancer.

RINC has established a Cervical Cancer Control Working Group and as of mid-2012 the governments of 13 Latin America countries are participating. Goals include:

- ▶ Providing a platform for technical exchange and consensus-building among member countries thereby strengthening prevention and early detection programmes.
- ▶ Reducing the incidence of and mortality from cervical cancer. An important virtue of the cooperation is that the consensus-building process serves to guide and validate

what network institutions seek to do in their own countries, giving them greater credibility with other stakeholders.

RINC also seeks to ensure support from international organizations and explore innovative financing for the rollout of its programmes. RINC has joined with the Pan American Health Organization/World Health Organization (PAHO/WHO), the US Department of Health and Human Services and the American Cancer Society to create the Cervical Cancer Prevention and Control Project for Latin America and the Caribbean which aims to reduce cervical cancer incidence and mortality through outreach to women in the region.

#### Box 3: Summary of Workshop 3

- ▶ The biggest barrier to move from evidence to practice is the lack of local evidence on how new interventions work in lesser-resource settings
- ▶ What has helped is conducting pilot projects to test and apply new interventions and creating consensus among all stakeholders
- ▶ The Women's Cancer Initiative offers an opportunity to advocate for more government investment in research and women's cancer programmes
- ▶ The Women's Cancer Initiative provides a good forum to share experiences between countries
- ▶ More implementation science and qualitative research related to women's cancers is needed

#### 4. Implementation science and health economics in the context of cancer control

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Given limited resources, decision-makers must consider the additional costs and value added of implementing new cancer control or prevention interventions. The field of dissemination and implementation research includes a focus on developing user-friendly tools and information to help decision-makers understand the tradeoffs between costs of adopting and implementing evidence-based programmes and expected health outcomes associated with new interventions. Several economic evaluation methods (e.g., cost-effectiveness, cost-benefit and cost-utility analysis) can be employed for this purpose so that data from these types of studies can be used to influence decision-making. There is an urgent need to translate evidence-based intervention programmes into

practice to reduce cancer morbidity and mortality; yet there are multiple competing demands that limit the ability for organizations to readily adopt and implement evidence-based programmes. Shifts in current research and practice are needed to increase the use of economic information to accelerate adoption, implementation and maintenance of evidence-based interventions for cancer control. First, while intervention trials more frequently include studies of intervention costs, cost-effectiveness, and budget impact, there is still an urgent need to make these types of measures and studies standard practice. Contextual factors, including organizational capacity, resources and infrastructure are also needed so that the results of economic evaluations can be interpreted appropriately and the potential for dissemination to new settings or population groups can be adequately assessed. Second, if this information is not made available to decision-makers following the completion of such studies, it cannot be used to facilitate adoption and implementation decisions. Therefore, it is essential to provide individuals responsible for making resource allocation decisions at the clinic, county, state and federal level with accurate information on the cost of implementing new interventions.

Researchers at the MD Anderson Cancer Center and the University of Texas School of Public Health are currently developing an innovative tool to help low-resource primary care clinics decide if they want to adopt an evidence-based tobacco cessation programme. Decision-makers at federally-qualified health centres and rural health clinics in Texas will be able to use this online tool to understand the cost implications of adopting and implementing Ask-Advise-Connect (AAC), an evidence-based tobacco cessation programme. Using the electronic health record, AAC prompts clinicians to assess the tobacco use status of every patient 13 years of age or older, advise him/her to quit and connect interested tobacco users directly and electronically to the Quitline. This tool will not only translate the findings of cost-effectiveness and budget impact information from previous studies but will do so in a format that will allow decision-makers to estimate clinic-specific costs and budget impact using their own data. Additional research is needed to test how these types of tools can be tailored to the needs of primary care professionals, and how they will be able to modify the key parameters of the model in real time depending on patient-, provider- or system-specific characteristics. Although the tool is being tested in the context of tobacco cessation, it can be applied to the planning and

application of other cancer prevention activities.

**Abstract 1: Lessons from the field: The making of a community-based programme of liver cancer prevention**

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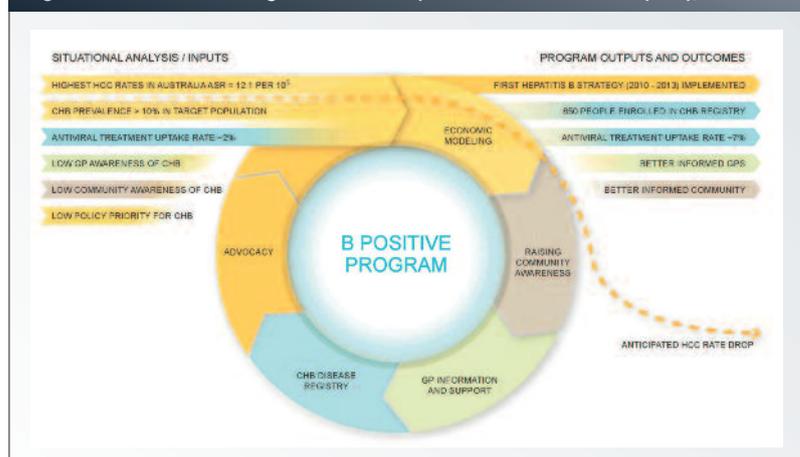
**Background**

Approximately 80% of hepatocellular cancers (HCC) worldwide are attributable to chronic viral hepatitis and are largely preventable, yet liver cancer remains a leading cause of cancer death in the Asian region and among migrant populations born in countries where chronic hepatitis B (CHB) infection is endemic. Although antiviral treatments can reduce HCC incidence, low disease awareness among affected communities and health care providers, logistical challenges, resource limitations and low policy priority preclude population-level approaches to disease control even in well-resourced settings.

**Methods**

The B Positive programme is a targeted, multi-pronged intervention aiming to reduce CHB-related HCC in high risk migrant communities in Sydney, Australia, where a rapid increase in HCC incidence recently propelled an uncommon cancer into the top 10 causes of cancer death. It combines community and primary care education and support with a CHB Registry which optimizes patient management and informs policy, practice and advocacy. The programme was informed by economic modelling showing that antiviral treatment for CHB is much more effective and cost-effective than primary liver cancer screening.

Figure 1: . The B Positive Program to reduce hepatocellular carcinoma in Sydney, Australia



### Results

The challenges arising from attempting to implement a “top-down” pilot intervention led to a wide stakeholder consultation and extensive programme re-design as a community-based programme which is commencing to change practice (see Figure 1). Programme achievements and lessons learnt during programme planning and development of potential relevance to cancer control in different settings were summarized.

#### *Abstract 2: Increased access to integral cancer care for poor and extremely poor people in Peru*

*Duniska Tarco Virto, Miriam Salazar Robles, Mariela Pow Sang, Marga Lopez Contreras, Millward Ubillus Trujillo, Julio Abugattas Saba and Tatiana Vidaurre Rojas, National Cancer Institute of Peru, Lima, Peru*

In 2009 the Peruvian government sanctioned the Universal Health Insurance (SIS) Law to provide financial protection to all Peruvians accessing a fixed set of services. However, poor and extremely poor people had rights to minimal services for cancer prevention and diagnosis. Despite the creation of a Fund for Catastrophic and High Cost Diseases (FISSAL), lack of financial resources, skilled professionals and diagnosis and treatment supplies in the poorest rural areas prevented the most vulnerable people from accessing integrated cancer care. In 2011, the Peruvian Ministry of Health and the National Cancer Institute (INEN) implemented a new model of output-oriented budget and cancer health delivery with new financial resources in five regions of the country for the prevention and early detection of breast, cervix, stomach, colon and prostate cancer. In mid-2012, the Peruvian government's National Cancer Program for the Poor and Poorest People provided access to preventive care and treatment (radiotherapy, chemotherapy and surgery). At INEN, the percentage of patients covered by public insurance (SIS) increased from an average of 5% in 2003–2009, to 18% in 2010, and 31% in 2011, mostly for risk prevention. It reached 41.1% by September 2012, when INEN and a strengthened FISSAL agreed to the financing of integrated cancer treatment for the seven most frequent types of cancer. In 2013, an increased proportion of poor people have accessed integrated cancer care – 59.46% by May 2013, with nearly 7,000 patients covered for early detection, stage-diagnosis and appropriate treatment. Currently, patients with leukemia and lymphoma are also covered for care including, if necessary, organ transplant by INEN's agreement with FISSAL (High Cost Sickness). The Peruvian government's groundbreaking political decision and INEN's technical leadership have resulted in an inclusive policy that

provides integrated quality cancer care for the poor and poorest families.

#### Box 4: Summary of Workshop 4

- Economic analysis should be included in all aspects of cancer control, from planning through implementation to evaluation
- Cost evaluation considerations can leverage political support for broad scale implementation of evidence-based cancer control, including provision of funding, technical assistance and interorganizational agreements to increase access to population health care
- The effectiveness and cost of strategies currently utilized to educate the population (e.g., “consejerias” counselling) require more evaluation
- Cost-effectiveness needs to be considered throughout programme implementation and evaluation
- Broadening the focus of cancer control to include primary and secondary prevention is supported by economic analysis
- Changes to population health practice, including universal coverage, benefit from inclusion of all key partners in policy development and implementation

### 5. NIH implementation science funding opportunities to rigorously evaluate the implementation of cancer control programmes in Latin American, African or Asian countries

*Cynthia Vinson and Michael Sanchez, Implementation Science Team, Division of Cancer Control and Population Sciences, National Cancer Institute (NCI), Bethesda, USA*

The National Institutes of Health (NIH) are committed to closing the gap between research discovery and community and clinical practice so that all populations can benefit from the investments made in scientific discoveries. As part of the NIH, the National Cancer Institute has dedicated staff in the Division of Cancer Control and Population Sciences that focus specifically on implementation science. Part of the Implementation Science Team's mission is to build the field of implementation science by growing the number of domestic and international dissemination and implementation research grants submitted for review and increasing the number of domestic and international grants funded by NIH.

To accomplish this goal, a number of conferences and training initiatives have been created to support investigators interested in conducting dissemination and implementation science research. NIH has hosted an annual conference on dissemination and implementation research in Bethesda, Maryland since 2007. This two-day conference is open to

domestic and international audiences. The conference combines a mix of plenary presentations with competitively selected oral presentations, poster presentations and think-tank sessions focused on an annual theme, such as “research at the crossroads” or “policy and practice in dissemination and implementation”. Interest in the conference has continuously grown with more than 800 individuals attending in 2012.

NIH has also co-sponsored an annual Training Institute on Dissemination and Implementation Research since 2011. This five-day training institute is also open to both domestic and international applicants who compete for 35 to 40 training positions. The training provides participants with a grounding in conducting dissemination and implementation science research in health. Faculty and guest lecturers consist of leading experts (practitioners and teachers) in theory, implementation and evaluation approaches to dissemination and implementation, creating partnerships and multi-level, transdisciplinary research teams, research design, methods and analyses appropriate for dissemination and implementation investigations and conducting research at different and multiple levels of interventions (e.g., clinical, community, policy). At the end of the training, participants are expected to return to their home institutions prepared to share what they have learned at the institute to help grow the field of dissemination and implementation research (e.g., giving talks, leading seminars, forming new collaborations, mentoring and submitting grant proposals).

NIH has a specific programme announcement (<http://grants.nih.gov/grants/guide/pa-files/PAR-13-055.html>) to fund dissemination and implementation research which is open to international applications. While training has helped build capacity for domestic researchers successfully competing for dissemination and implementation grants at NIH, the number of international applications has not grown significantly.

This was a small hands-on workshop for delegates interested in securing funding for implementation science research. The workshop provided information about research topics and methods to study dissemination and implementation of cancer control programmes and policies. Delegates were encouraged to come to the workshop with a dissemination and implementation research project in mind. An overview of dissemination and implementation research along with information concerning the NIH grant submission process with a focus on international applications was provided. Delegates spent time with facilitators working on potential grant application abstracts and shared ideas for potential research projects with the larger group.

#### Box 5: Summary of Workshop 5

- NIH wants to encourage international researchers to submit dissemination/implementation research grants. Interested individuals should contact Cynthia Vinson ([cvinson@mail.nih.gov](mailto:cvinson@mail.nih.gov))
- Applying for implementation science grants from NIH is a challenge for foreign institutions – the implementation science team at the NCI is working to improve success rates for these institutions

### Discussion and conclusions

*Cynthia Vinson, Implementation Science Team, Division of Cancer Control and Population Sciences, National Cancer Institute (NCI), Bethesda, USA, and Luiz Santini, Instituto Nacional de Câncer (INCA), Rio de Janeiro, Brazil*

Challenges for integrating research with practice and policy exist in both HICs and LMICs. Common issues include:

- developing and implementing practical measures for setting priorities and tracking progress;
- identifying appropriate evidence-based interventions and policies;
- understanding the processes for successfully implementing evidence-based interventions.

Session 5 (ICCC-5) identified opportunities for improving the integration of research into practices and policies in both HICs and LMICs.

Traditional surveillance systems are necessary but insufficient for measuring progress in achieving cancer control goals. Practical measures that can show progress towards goals in the near term are critical for gaining ongoing support for cancer programmes and policies. The World Cancer Declaration Targets (19) are an example of implementation of practical measures at the international level. Further approaches were highlighted in Canada and Peru. Health economics data are one type of practical measure that was seen as critical for gaining political support, developing evidence-based policies and programmes and reporting outcomes of interest to the public. Economic analysis should be included from the planning stage through implementation and evaluation of cancer control programmes. Workshop discussion identified the need to develop the field of health economics in Latin America and other LMICs, a role that might be appropriate for regional cancer control groups such as RINC or PAHO.

Pragmatic approaches for integrating research into practice and policies through partnership models such as the Women’s Cancer Initiative highlighted the need to ensure input from

relevant stakeholders to ensure research findings are relevant to the needs and challenges of specific populations or settings and the necessity to coordinate pilot projects and create forums for testing and applying new interventions to establish consensus, action and implementation of effective interventions.

Finally, understanding the processes for successfully implementing evidence-based interventions is necessary for integrating research into practice and policy. One approach is the creation of communities of practice around cancer control programmes and policies that include researchers, practitioners and policy-makers. These communities of practice can provide a space for open dialogue on the realities of moving research into practice, identification of the needs and priorities of the key stakeholders and a place to explore opportunities to collaborate on research designed for real world practice. Funding is important for dissemination and implementation of research findings as well as for studying optimal processes for dissemination and implementation.

Given the relevance to population health, greater government support for cancer control research is particularly germane rather than relying on research generated by corporate interests.

#### Acknowledgments

*This manuscript is a synthesis of plenary presentations, workshop discussions, including selected abstract presentations, and recommendations for ongoing actions derived from Session 5 of the Fifth International Cancer Control Congress (ICCC-5) held in Lima, Peru, 3-6 November 2013. The ICCC-5 Working Group was made up of Simon B Sutcliffe, Kavita Sarwal and Catherine G Sutcliffe from the International Cancer Control Association, and Tatiana Vidaurre Rojas and Roxana Regalado from the National Cancer Institute (INEN) in Peru. The opinions expressed herein represent those of the authors alone and do not necessarily represent the institutions and organizations by which they are employed.*

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# APPENDIX

## THE ROLE OF INTERNATIONAL CANCER CONTROL CONGRESSES ON PARTICIPANT BEHAVIOUR AND ACTIVITIES

# THE ROLE OF INTERNATIONAL CANCER CONTROL CONGRESSES ON PARTICIPANT BEHAVIOUR AND ACTIVITIES

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**Objective:** Assess whether congresses affect participant behaviour and/or activities.

**Method:** The International Cancer Control Congresses (ICCCs) provided a "natural experiment" to assess the value of international conferences and examine ways to influence positive change, policy and practice to enhance cancer control. We studied the responses of registered participants for two Congresses (ICCC-3 and ICCC-4) using the primary data collection instrument as self-report surveys, on-site surveys and follow-up surveys a few months later on the same census sample of participants.

**Results:** Most respondents gained professionally through improved understanding of global population-based cancer control programmes and new insights into cancer control. Through sharing best practices and insights gained at the Congress in their jurisdictions, many increased awareness for establishing collaborations, implementing surveillance systems and expediting integrated national cancer and noncommunicable disease plans. Participants continued to experience increased interest and involvement in cancer control through their networks.

**Conclusions:** Findings revealed that it takes time before initiatives emerge that derive from ICCC-attributable participation. Longitudinal cohort studies could offer greater insight into factors influencing the value of conferences and establishing contribution to cancer control activities.

**Key words:** *Evaluation; conference evaluations; impact of conferences; cancer control; logic model*

## Introduction and objectives

Noncommunicable diseases, including cancer, are one of the most serious health challenges the world faces today. By 2030, deaths from noncommunicable diseases (NCDs) are expected to account for 69% of all global deaths with cancer deaths increasing to 11.8 million from 7.4 million in 2008 (1). At present, NCDs are responsible for about 63% of global deaths – 36 million of 57 million global deaths, with greater than 60% occurring in lower- and middle-income countries (LMICs) resulting from population ageing, urbanization and globalization of risk factors (2,3). A global call for action to reduce the impact of NCDs, including cancer, by 25% by 2025 propelled the development of the Global Action Plan 2013–2020 at the Sixty-sixth World Health Assembly (4).

Experiences gained from planning and implementing disease control programmes in developed countries can help developing countries in addressing the growing NCD burden (5,6). Two theoretical concepts through which population-based cancer/NCD control might be enhanced are capacity-building (CB) (7,8) and communities of practice (CoP) (9–12).

The recent Sixty-sixth World Health Assembly (WHA) also called upon members to focus efforts on building capacity and approved a resolution calling on all Member States to put in place plans to control cancer and NCDs (4,13). Tracking progress of CB can be done through three types of indicators: service development, sustainability and increased problem solving capacity (14).

Communities of practice foster the exchange and sharing of problems, insights and solutions between participants from low-, middle- and high-income countries through collaborations and establishment of partnerships to address mutually desirable goals. CoPs may develop from these partnerships, but vary greatly from informal networks to formal structured teams. The core elements that develop and sustain a CoP are a sense of belonging, participation and collaboration (9,10,12,15).

International Cancer Control Congresses (ICCCs) present a forum where participants share knowledge, experiences, approaches and best practices that can enhance the implementation of sustainable population-based national cancer control strategies and, more broadly, noncommunicable disease (NCD) agendas. Congresses (1) may foster engagement between low-, middle- and high-income countries through involvement of diverse individuals in the

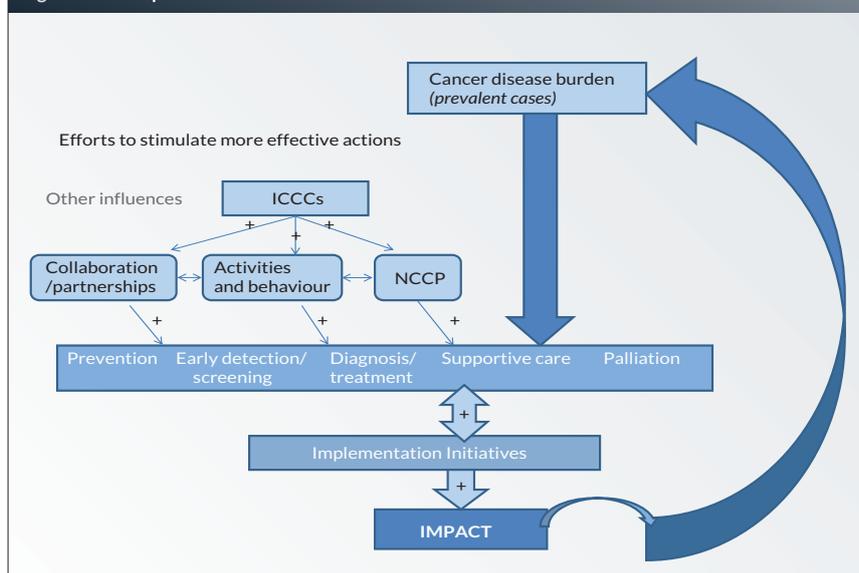
congress committees and activities. ICCCs have provided a “natural experiment” to assess whether a meeting addressing a significant global health challenge can improve policy and practice related to cancer control.

ICCCs deploy a logic model to determine why and how congresses are being conducted as well as their desired outcomes. The logic model builds upon past Congress experiences to understand how participant behaviours and activities influence population health and disease control, to enhance capacity, strengthen alliances and promote concerted efforts to address risk factors for cancer/NCD prevention and control. The model specifies a set of measurements which are useful for assessing the planning and execution of the ICCC.

Figure 1 illustrates how the ICCC encourages action by influencing changes in (a) participant activities and behaviour, including their role in enhancing population-based cancer control, (b) establishing an appropriate agenda promoting collaborations and partnerships, and (c) raising awareness of participants to the importance of developing, implementing or strengthening national cancer control programmes. This awareness contributes to stimulating efforts undertaken to address cancer along the cancer control continuum. Short-term outcomes include host country/region demonstrating increased commitment to cancer control, preparation of scientific manuscripts for publication, etc. The long-term expected outcomes include an increased global outreach and collaboration and initiation of mechanisms to help countries develop and implement cancer control action plans or programmes (16–18).

Typically, evaluation of congresses addresses logistical arrangements, information perceived to be learnt by participants and how the information was provided at the

Figure 1: Conceptual schema



congress (19–22). However, few address the short- and long-term impact using an evidence-based approach. This paper assesses whether ICCCs affect individual behaviours/activities, whether individuals from differently resourced countries see a different “value-add” of the congresses and, finally, if or how much of the change in behaviour/activities can be attributed to participants having attended the Congress (23).

## Method

The study was conducted between November 2009 and January 2012 on 362 individuals participating in the Third ICCC and 310 participants from the Fourth ICCC. The study explored the Congresses’ influence on changes in participants’ activities and behaviours, formation of communities of practice (CoPs), knowledge transfer and development/implementation of national cancer control plans.

The study design involved conducting a self-reported questionnaire survey at the ICCCs to individuals registered on the database. The unit of analysis for the study was individuals participating in each of the Congresses. To confirm changes in behaviour and activities of the participants an on-site survey was followed two to three months post-Congress by a follow-up survey conducted on the same group of registered Congress participants. The first survey was conducted on-site at ICCC–3 in November 2009. A follow-up survey was conducted using a mailed, self-administered electronic questionnaire. The third survey was conducted at ICCC–4 on-site in November 2011. This was followed by the fourth and final follow-up survey. These surveys helped to understand the impact of the Congress on the participant activities and behaviours and their influence in turn on cancer control planning and implementation (24). For details refer to Table 1.

This was a series of cross-sectional studies as different individuals attend each Congress with little overlap between the participants. The follow-up surveys did not link the original respondent to his/her earlier answers. The study had two sets of individuals with few attending both Congresses.

The study involved a concurrent collection of qualitative

and quantitative data from surveys, validation of quantitative results with qualitative results and merging of the data during the interpretation/ analysis – a variant “triangulation design-validating quantitative model” (25–30).

The on-site and follow-up surveys had 26 and 33 questions respectively. They sought brief demographic facts, perceived benefits of congress attendance, the impact of the congress at an individual, organizational and country level and information about the participants’ experience at the Congress generally, using a five-point Likert scale. The data was analysed using the statistical package SPSS Statistics 17.0. Univariate and bivariate analyses were conducted for each of the surveys to explain the distribution of responses and determine the statistical significance of relationships between variables. The study used cross-tabulation and Pearson’s chi square tests for determining if a statistically significant relationship existed.

Primary data were supplemented with secondary data that included Congress publications and recent country profiles published by WHO. The secondary data obtained from Congress Proceedings, the Congress Analysis Reports, WHO NCD Country Profiles (31) and other appropriate web-based publications was used for qualitative analysis with NVivo 9.

## Results

Findings from the univariate analysis from the four reports and the supporting qualitative data revealed over 60% participants were from high-income countries and there was a large representation from the country where the meetings were held. At ICCC–3, 24% (n=86/362) were from Italy and at ICCC–4, 48% (n=150/310) were from the Republic of Korea.

The largest group of participants was researchers and scientists, followed by clinician/physicians. Over half the participants were from governmental organizations and 7–14% of these were policy-makers. The next predominant representation was from nongovernmental organizations (NGOs). Over 45% of the participants had worked in cancer control for more than 11 years. “Improved understanding of population-based cancer control programmes globally” and “new insights into cancer control strategies and population-

Table 1: Participation details for the Congresses

	3rd ICCC (ICCC–3) On-site survey	3rd ICCC (ICCC–3) Follow-up survey	4th ICCC (ICCC–4) On-site survey	4th ICCC (ICCC–4) Follow-up survey
Scheduled	November 2009	July 2010	November 2011	February 2012
# Participants	362	362	310	310
# Countries Represented	65	38	44	37
# Survey Respondents	171	112	110	106
Survey Response Rate	47%	31%	35%	34%

based systems” were the two primary professional gains for participants in all four surveys.

In the follow-up surveys, 88% and 93% participants in ICC3-3 and ICC3-4 respectively expressed being influenced to “some extent” by the Congresses, indicating that a large proportion of attendees participated in activities/programmes related to cancer control as a result of the Congress. When asked if their involvement and interest in cancer control had changed after ICC3-4, 73% stated the change in interest and

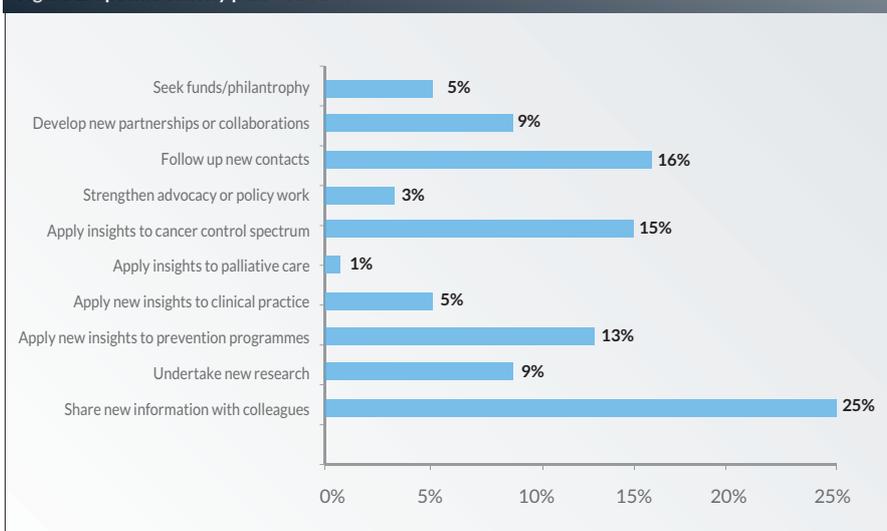
involvement was “more than before” but 26% indicated that it did not change at all. A majority (83% following ICC3-3 and 95% following ICC3-4) found that their cancer control work had benefited by attending the ICC3. Also, after each of the congresses participants “agreed to strongly agreed” that the Congress had provided a platform for knowledge exchange for cancer control and had helped them primarily with creating collaborations (83%), sharing best practices to develop cancer control plans and with raising awareness of cancer control.

More than 50% (ranges from 50–91%) of participants in the follow-up (1) to ICC3-3 and ICC3-4 stated that they had used the knowledge gained from ICC3 from “some to a great extent” in sharing new information, developing new partnerships, following new contacts, applying new insights to cancer control planning, strengthening advocacy or policy work and applying new insights to prevention programmes. Eighty-five percent of participants shared the information with colleagues post-Congress.

Two-thirds (66%) of respondents to the ICC3-3 follow-up survey indicated that their involvement and interest in population-based cancer control was “more than before”, but 34% said “not at all”. A high proportion of ICC3-3 follow-up survey respondents (88%) reported that their level of interest and involvement had been influenced by Congress attendance “to some extent or to a great extent”, indicating that a large proportion of attendees participated in activities/programmes related to cancer control following Congress attendance. Nearly three-quarters (73%) of respondents to the ICC3-4 follow-up survey reported that their interest and involvement in cancer control increased as a result of Congress participation.

An analysis demonstrated that an association exists between the satisfaction expressed with ICC3-4 and the

Figure 2: Specific activity plan – ICC3-4



subsequent pursuit of direct follow-up plans as a result of the Congress. It revealed that those expressing “a great extent” of satisfaction (27 of 71) were far more predisposed to pursuing follow-up plans “to a great extent” than those who indicated satisfaction of only “to some extent” or “not at all” (4 of 39 cumulatively). Participants who expressed satisfaction with the Congress were in the majority compared to the 3% of respondents who expressed being “not at all” satisfied ( $p=0.001$ ).

Participants’ desire to be aware of the current state-of-the-art clinical and scientific content provided at the Congress was associated with their contribution, opportunity and ability to raise awareness of cancer control in their country. Of the 105 respondents, 86 (82%) came to participate in ICC3-4 to be aware of the current state-of-the-art clinical and scientific cancer control content. Sixty-three percent of this subgroup “agreed” and 26% “strongly agreed” that attending ICC3-4 helped them in contributing to and creating a way to raise awareness of cancer control in their country. Nineteen (18%) of the 105 respondents did not identify the awareness of current clinical and scientific content as a priority for attendance; 42% of this subgroup “agreed” that attending ICC3-4 helped them in contributing to and creating ways to raise awareness of cancer control in their country ( $p=0.004$ ).

Figure 2 identifies the specific activity participants said that they would most likely do with the information gained at ICC3-4. From the ten shortlisted activities, 25% of participants said they would share information gained from ICC3 with colleagues, 9% indicated they planned undertaking new research, 13% intended applying new insights to prevention programmes, 5% would apply new insights to clinical practice, 1% planned applying new insights to palliative care, 15% applying new insights to cancer control practices,

3% would strengthen advocacy or policy work, 16% deliberated following up with new contacts, 9% planned developing new partnerships or collaborations and 5% would seek philanthropy/foundation funds/establish charitable connections.

In the ICCC-4 follow-up survey participants were asked to self-report actions they had said they would undertake at the Congress. Over 50% of participants reported having used the knowledge gained from ICCC-4 to some extent in all the parameters mentioned in the figure. Nearly a quarter of participants used the information to a “great extent” in applying new insights to cancer control planning, sharing new information, following up with new contacts, applying new insights to prevention programmes, increasing advocacy and developing new partnerships. When questioned whether their involvement and interest in cancer control had changed after ICCC-4, 60% participants said “to some extent” and 33% said “to a great extent”.

Income level of country of work (low-, middle- and high-income) was associated with change in participant interest and involvement in cancer control after ICCC-4 ( $p=0.04$ ). Of the 105 respondents, 39% were from high-income countries, 56% from middle-income countries and 5% from low-income countries. A higher proportion of respondents from low-income countries reported being interested “more than before” ( $n=6$ ) and 81% respondents from middle-income countries said their interest levels in cancer control increased through Congress participation compared with 59% from high-income countries.

ICCC-3 and its follow-up survey revealed that participants’ change of involvement and interest in cancer control work by attending ICCC-3 was associated with the extent to which cancer control was part of the participants’ work ( $p=0.044$ ). Two thirds of respondents (66%) were more interested in cancer control after attending ICCC-3 but 34% experienced no change in involvement.

After attending ICCC-3, 23% indicated that they would share the new information with colleagues, 27% said they would use it in collaborating (i.e., following up with new contacts or developing new partnerships), 7% intended to undertake new research, 12% planned to apply the new insights to prevention programmes, 6% were planning to apply the new insights to palliative care, 10% were deliberating application to cancer control work, 9% intended to strengthen their advocacy efforts and 2% were planning to establish charitable connections.

Following ICCC-3, 85% of the participants have shared the information they gained at the Congress. Most applied to “some extent or to a great extent” their newly gained

knowledge in parameters like undertaking new research, applying new insights to prevention programmes and cancer control planning, strengthening advocacy work, following up with new contacts and developing partnerships. Information pertaining to applying new insights to clinical practice (30%), applying new insights to palliative care (29%) and fundraising (25%) have been used significantly only by a small portion of attendees.

After attending ICCC-3, a delegate from Egypt shared that the Congress inspired him to initiate a pilot programme for palliative care and another delegate identified that even though his work focus still needed to be on direct patient care, his appreciation of broader issues of cancer control had improved, as reflected in his teaching, leadership and supervision. The ready accessibility of ICCC presentations on the Congress website allowed a delegate from New Zealand to circulate reports after each Congress, summarizing key contacts, presentations and issues of interest/relevance to colleagues. A majority of participants at all ICCCs believed that the ICCCs had helped them professionally and that they had been positively influenced by attending the Congress.

Survey results of ICCC-3 and ICCC-4 confirm that well over half the respondents have found the Congresses to be “successful to very successful” (86% and 68% respectively) in achieving their objectives of sharing best practices and promoting evidence to develop cancer control plans, national cancer control policies, creating ways to collaborate and raise awareness of cancer control, providing a setting for relationship building and providing a platform for knowledge transfer for cancer control. The follow-up survey results demonstrated that respondents rated ICCC-3 (84%) and ICCC-4 (83%) as having helped them with behaviours such as creating collaboration, knowledge transfer, raising awareness and sharing best practices.

Qualitative findings reveal participant comments were of two types: concrete actions and personal development comments. Personal development comments ranged from the usefulness of exchanges of practical experiences, to comments on knowledge transfer. For example, IAEA-PACT shared the evolution of global activities for the Programme of Action for Cancer Therapy (PACT) and its close association with ICCCs.

Only some participants shared specific cancer control activities they had initiated or participated in following the Congress through follow-up surveys. These included cancer screening programmes, advocacy for cancer control, building collaborations, establishing networks to exchange experiences and reaching out for support. Some countries were also developing, updating or implementing national cancer control/integrated NCD plans and strengthening

cancer control/NCD programmes. Irrespective of the resource level of the country, respondents consistently indicated that there were ongoing cancer control activities in their countries.

Brazil established a Regional Community of Practice in Cancer Control following ICCC-1 and ICCC-2 – the Latin American and Caribbean Alliance for Cancer Control (including Argentina, Brazil, Chile, Colombia, Costa Rica, Cuba, Mexico, Nicaragua, Peru and Uruguay (32) and the subsequent development of the Network of National Cancer Institutes (RINC) in Latin America (33). Formation of this alliance also led to the signing of the Rio de Janeiro Declaration, affirming regional collaboration in areas of common interest related to cancer prevention and control (32).

The Cernobbio Declaration to sustain cooperation on cancer control was presented and signed at ICCC-3 (2009) by participants and shared with the European Union (EU) to highlight the need to focus and allocate funding for cancer control in Europe (17, 34). At a European level there continues to be further integration of different EU-funded projects like Eurocare, Eurochip, Eurocourse and others (35).

Following both Congresses, more than 80% of participants believed they had gained new insights into cancer control strategies and population-based systems and were sharing new information with colleagues. Over 60% believed they were applying new insights to prevention programmes and cancer control and following up on new contacts.

The logic model developed for the Congress served as a visual communicator that guided what should be assessed and measured and enabled exploration of a chain of cause and effect (36). Using the logic model approach (37, 38) the Congress led to activities which then generated outputs, outcomes/effects/results that led to impacts.

## Discussion and conclusion

Over the period of 2005–2011, the Congresses have evolved to increasingly recognize the need for the integration of cancer and NCD control: primary, community and tertiary care; interprofessional and interdisciplinary practice; public and population health and clinical medical practice; and strategic, business and operational plans to control cancer. This study has examined the value attained through Congress attendance with respect to participant engagement in activities and behaviour that might lead to enhanced population-based cancer control.

A conclusion supportive of the Congress enabling an enduring impact at an individual participant level cannot be derived. However, since alliances, memoranda of understanding, signed declarations and formalized cancer

control networks have resulted from ICCC-2 and ICCC-3 at a country and/or regional level, the Congress may be perceived as a forum that has facilitated achievement of an enduring impact in the host region.

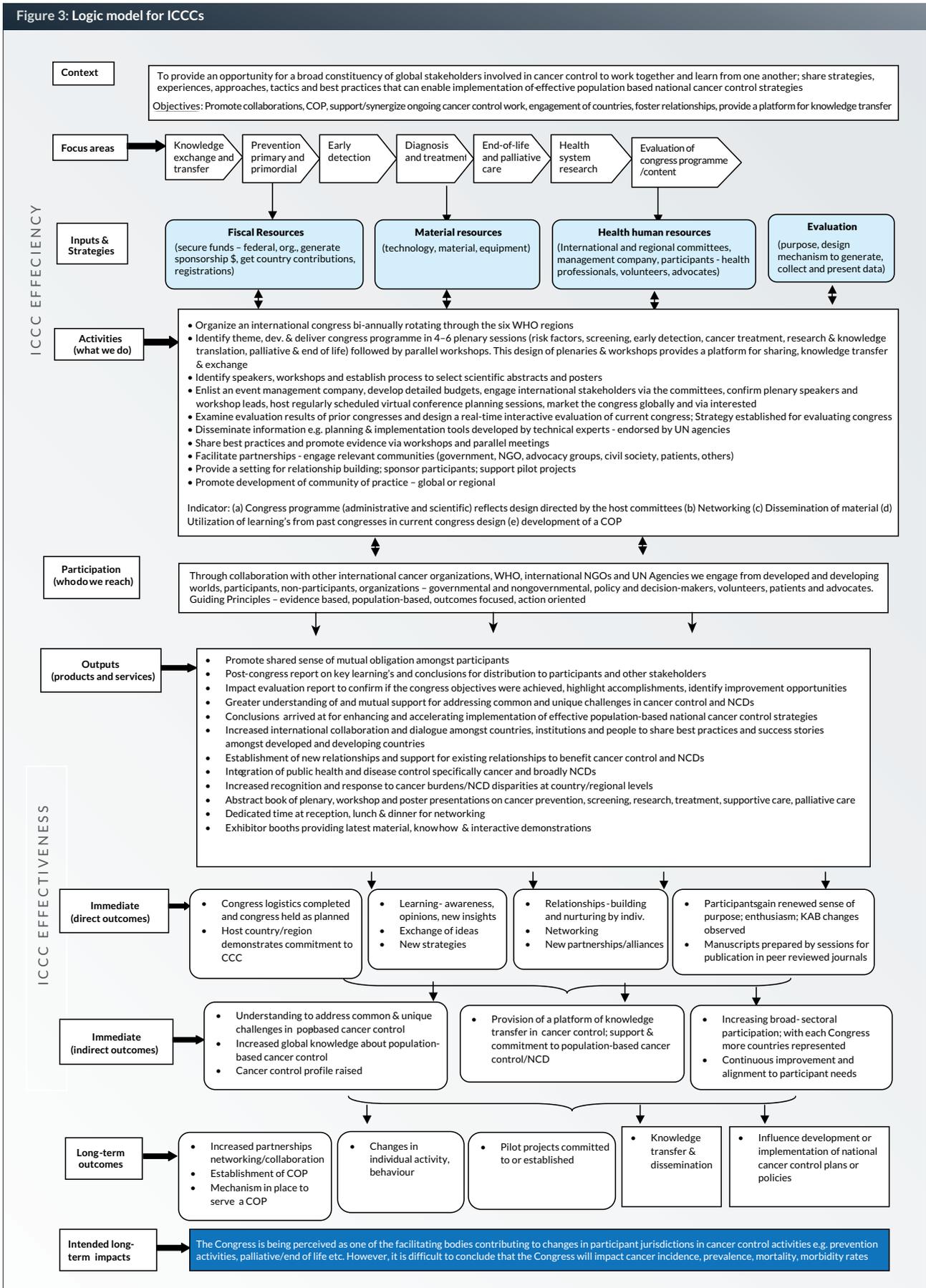
Through the interactive workshops, attendees were able to assimilate ideas that they could take back and apply within their spheres of influence. Thus, most viewed ICCCs as a catalyst that highlighted and supported capacity-building efforts by countries; and promoted use of toolkits, such as the WHO Stepwise Framework (39, 40) to bring change in integrated cancer/noncommunicable activities by undertaking or strengthening national cancer control planning and initiating or enhancing targeted cancer control programmes, knowledge translation and research activities. Though not all individuals identified specific activities they were undertaking, it appeared that they were at least engaged.

Due to the study not being longitudinal it cannot be definitively determined whether any individual-level contacts established during the Congress actually continued to foster and give rise to concrete cooperative efforts visible in the future. However, the present study found that a significant number of participants undertook activities they said they would be doing based on the insights gained at the Congress. Examination of the information from the analysis did support that ICCCs influenced reported changes in activities and behaviours of participants.

It was difficult, however, to determine the extent of the influence on the demonstrated changes in behaviour and activities and the extent and sustainability of the resulting actions or knowledge translation measures on population-based cancer control programmes and collaborations. Interpretable constraints include the limited time available for the current study and the cross-sectional design rather than a prospective, longitudinal cohort study.

The present study found that attendees from low- and middle-income countries were more satisfied with the Congress than attendees from high-income countries. Over 60% of the participants following both Congresses found their involvement and interest in cancer control had changed; over 50% of participants expressed that their level of interest and involvement in cancer control was to some extent influenced by attending ICCC and over 30% experienced an increase in their network/collaborations following ICCC. Correlation with country resource levels confirmed that attendees from low- and middle-income countries experienced a greater change, were influenced by ICCC to a greater extent and there was a greater increase in their collaborations/networks. Inferentially, participants from low- and middle-income

Figure 3: Logic model for ICCCs



countries may derive greater value from experiences relevant to developing, resource-constrained nations.

This study affirms that ICCC provides a forum for knowledge transfer/exchange. Participants noted that after each congress, they have continued contact with individuals from whom they have sought advice or information as a result of meeting them at the Congress. Attending ICCC has provided the opportunity to be able to step outside of national and organizational contexts and reflect on key issues from an international “system” perspective.

Most of the respondents gained professionally in improved understanding of global population-based cancer control programmes and new insights into cancer control. The importance of national cancer/integrated NCD plans and the value of increasing networks was reinforced.

This study demonstrated that discussions at the Congresses contribute to transfer of knowledge among participants and bring the focus and raised awareness to the needs and

benefits of population-based cancer control initiatives and NCCPs. Through raising the profile of NCCPs, stakeholders have realized the increasing strategic importance of dealing with cancer and NCDs, as reflected in the UN-ratified Global Action Plan (4). The findings from this study provide information to strengthen the value of health care congresses. The derivation of a congress logic model may serve as a useful framework for other global conferences.

In conclusion, through use of a logic model approach, ICCCs have demonstrated the importance of evaluation of a congress in relation to defined objectives. Logic models require minimal resources yet provide the necessary details required for planning an effective congress and facilitate a clear understanding of desired outcomes, future challenges, current resources and timelines (36–38). The planned evaluation of ICCCs has revealed the value of congresses in addition to assessment of attendance, income, satisfaction with speakers and other logistical parameters.

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# THE FIFTH INTERNATIONAL CANCER CONTROL CONGRESS

The Fifth International Cancer Control Congress took place in Lima, Peru, from the 3-6 November 2013 and was organized by the International Cancer Control Congress Association.

The five sessions covered the following topics:

- Improving and sustaining prevention in cancer control
- Mobilizing “all of society” for effective cancer control
- Improving population health: Using data and evidence to support policy and programmes
- Improving integrated approaches to cancer treatment and care
- Integrating research, practice and policy priorities to improve cancer control