
THE FIFTH INTERNATIONAL CANCER CONTROL CONGRESS

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 Parascandalo 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

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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

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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

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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

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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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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

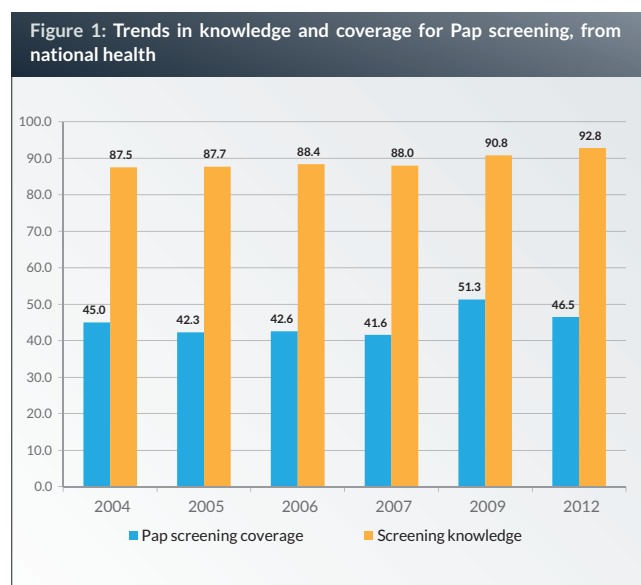
in these low-resource settings.

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

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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.

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