

# A training programme to build cancer research capacity in low- and middle-income countries: findings from Guatemala

Lauren D Arnold,<sup>a</sup> Joaquin Barnoya,<sup>b</sup> Eduardo N Gharzouzi,<sup>c</sup> Peter Benson<sup>d</sup> & Graham A Colditz<sup>b</sup>

**Problem** Guatemala is experiencing an increasing burden of cancer but lacks capacity for cancer prevention, control and research.

**Approach** In partnership with a medical school in the United States of America, a multidisciplinary Cancer Control Research Training Institute was developed at the *Instituto de Cancerología* (INCAN) in Guatemala City. This institute provided a year-long training programme for clinicians that focused on research methods in population health and sociocultural anthropology. The programme included didactic experiences in Guatemala and the United States as well as applied training in which participants developed research protocols responsive to Guatemala's cancer needs.

**Local setting** Although INCAN is the point of referral and service for Guatemala's cancer patients, the institute's administration is also interested in increasing cancer research – with a focus on population health. INCAN is thus a resource for capacity building within the context of cancer prevention and control.

**Relevant changes** Trainees increased their self-efficacy for the design and conduct of research. Value-added benefits included establishment of an annual cancer seminar and workshops in cancer pathology and qualitative analysis. INCAN has recently incorporated some of the programme's components into its residency training and established a research department.

**Lessons learnt** A training programme for clinicians can build cancer research capacity in low- and middle-income countries. Training in population-based research methods will enable countries such as Guatemala to gather country-specific data. Once collected, such data can be used to assess the burden of cancer-related disease, guide policy for reducing it and identify priority areas for cancer prevention and treatment.

Abstracts in **عربي**, **中文**, **Français**, **Русский** and **Español** at the end of each article.

## Introduction

A disproportionate burden of the recent global increase seen in cancer incidence and mortality is shouldered by low- and middle-income countries (LMICs). This is due in part to population ageing in LMICs, but shifts in the prevalences of modifiable risk factors – such as smoking and obesity – have also played a role.<sup>1</sup> The United Nations and the Pan American Health Organization (PAHO) cite cancer surveillance, research and capacity building in LMICs as critical elements in the prevention and control of cancer worldwide.<sup>2–4</sup> The World Health Organization (WHO) has emphasized the importance of capacity building that reaches beyond the development of infrastructure and resources to include the strengthening of in-country competence for conducting high-quality research.<sup>5</sup> Potter & Brough developed a “capacity model” that addressed the building of infrastructures, systems, skills and tools, particularly in LMICs.<sup>6</sup> In this article, we illustrate one application of this “Potter–Brough” model that is responsive to the cancer needs of Guatemala – a lower-middle-income country in Latin America.

### Guatemala: context for capacity building

Although cancer is the third leading cause of mortality in the country,<sup>7</sup> Guatemala lacks a population-based surveillance system<sup>7</sup> and only has limited services for cancer prevention and control. According to WHO – which has used Guatemala as an example of a country with a critical need to incentivize health

research – the retention of “clinician researchers”, research that informs policy and systems changes, and institutional commitment are all key to building cancer research capacity in the country and addressing the country's cancer needs.<sup>8</sup>

The *Instituto de Cancerología* (INCAN) in Guatemala City serves as the point of referral and service for Guatemala's cancer patients. Access to adequate medical care in general – and oncological care in particular – is so poor in many areas of Guatemala that most cancers are not diagnosed until they are advanced. More than 70% of INCAN's patients present with late-stage disease. The country's oncologists are keen to develop strategies to reduce the late-stage diagnoses and improve outcomes. Although INCAN focuses on diagnosis and treatment and collects no population-based data, its medical records currently provide the best data available for estimating the national cancer burden in Guatemala.<sup>9</sup> Recently, INCAN's administration expressed an interest in collecting better, population-based data on which more accurate estimates of the country's cancer burden – and more effective initiatives for cancer prevention and control – could be based. INCAN is slowly developing into a resource for the development of agendas for the future prevention and control of cancer in Guatemala.

## Training programme

In a partnership between INCAN and the School of Medicine of Washington University in Saint Louis (Saint Louis, United

<sup>a</sup> College for Public Health and Social Justice, Saint Louis University, 3545 Lafayette Avenue, Saint Louis, MO, 63104, United States of America (USA).

<sup>b</sup> School of Medicine, Washington University in Saint Louis, Saint Louis, USA.

<sup>c</sup> Instituto de Cancerología, Guatemala City, Guatemala.

<sup>d</sup> College of Arts and Sciences, Washington University in Saint Louis, Saint Louis, USA.

Correspondence to Lauren D Arnold (e-mail: larnold7@slu.edu).

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States of America), the Cancer Control Research Training Institute was developed at INCAN in September 2010. This was in response to Guatemala's increasing cancer burden and INCAN's recognition of the need to train clinician researchers in population health methods – so that such individuals can study and address Guatemala's cancer needs. The long-term goal is to establish a sustainable training programme to develop capacity for research that could improve cancer-related policy health systems and disease management. Key features of the year-long programme described here included multidisciplinary training, didactic sessions, a mentored dyadic experience and applied training through the development of research protocols that are responsive to Guatemala's needs (Fig. 1).

For the first, year-long training programme, 10 clinicians – five from the United States and five from Guatemala – were selected to participate, via a competitive application process. Participants engaged in training sessions – in

English – in biostatistics, epidemiology, research methods, data collection and management, ethics and anthropology. The participants were separated into five pairs – each comprising a clinician from Guatemala and one from the United States – and each pair was matched with a mentor who was a member of the academic staff at the School of Medicine of Washington University in Saint Louis. Via e-mails and voice-over-Internet-protocol conversations, each pair and its mentor developed an early-stage research project that addressed a cancer need in Guatemala.

## Capacity-building model

### Structures and systems

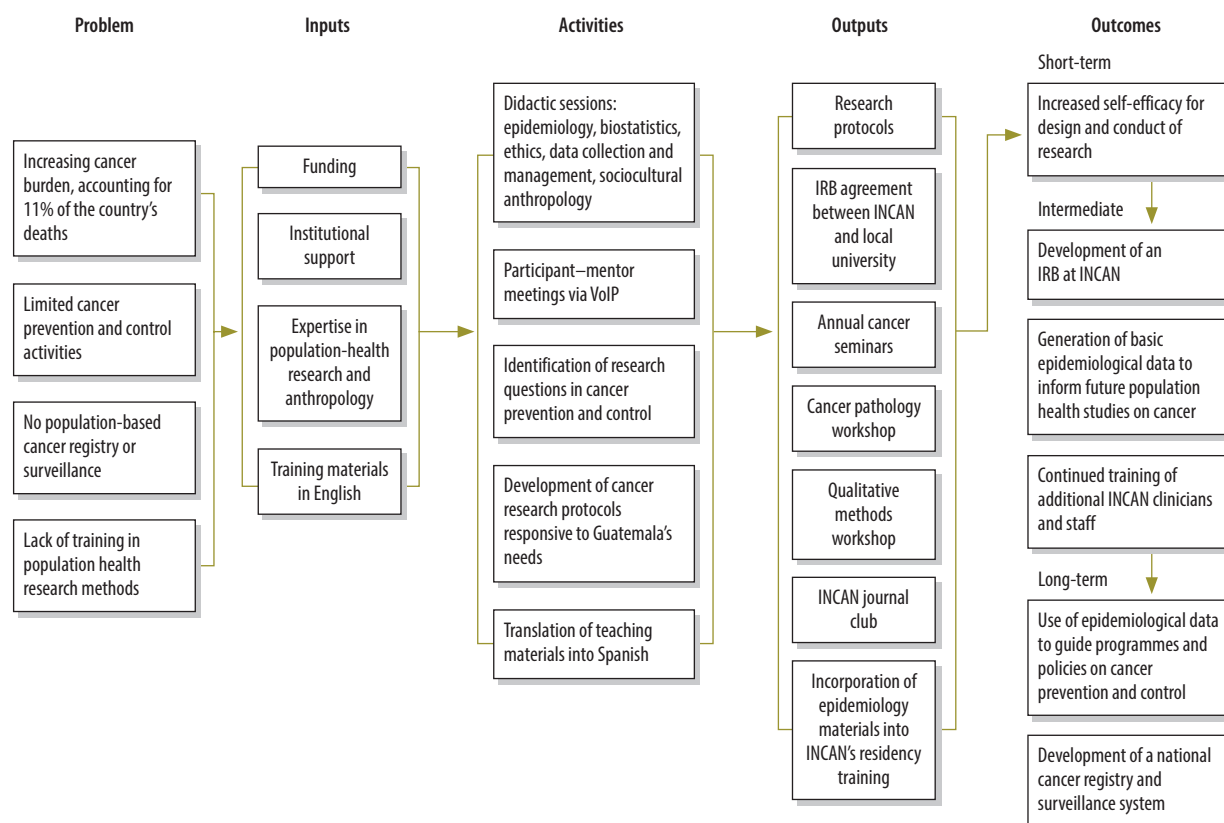
At the “ground level” of the Potter-Brough model are the structures, systems and roles that address information flow and the authority to make decisions.<sup>6</sup> A key component of the Cancer Control Research Training Institute was the “buy-in” from INCAN's leadership

and the *Liga Nacional Contra el Cáncer Guatemala* – INCAN's sponsor. Also crucial was a train-the-trainer model, in which a member of INCAN's staff who had decision-making authority participated in the training programme. As INCAN does not have an institutional review board, it was arranged for a Guatemalan university – the *Universidad Francisco Marroquín* – to review the research protocols that were produced in the training programme. Although this arrangement set the foundation for research in the near future, INCAN's administrators recognized the importance of establishing their own institutional review board to sustain the research capacity that they aim to build.

### Staff and infrastructure

The second level of the Potter-Brough model addresses the presence of facilities, resources and staff to support the work being done. Our training programme relied on on-site training in two countries and Internet-based communications. These activities required

Fig. 1. Building cancer research capacity, Guatemala, 2012



INCAN, *Instituto de Cancerología*; IRB, institutional review board; VoIP, voice over Internet protocol.

Note: the figure shows a logic model used for a year-long training programme for clinicians. The programme was based at the newly established Cancer Control Research Training Institute – a joint endeavour of the INCAN in Guatemala City and the School of Medicine of Washington University in Saint Louis (Saint Louis, United States).

classrooms, academic staff, computer access and support and Internet connections that supported “online meetings”. We had to identify academic staff who were willing and able to add new responsibilities – trainee instruction and mentoring – to their workloads. A careful examination of existing work schedules was key to solidifying the commitment of academic staff. Administrative support for travel, scheduling and financial logistics was provided by Washington University in Saint Louis.

### Skills

The third tier of the Potter–Brough model involves the building of individual-level knowledge, skills and confidence to engage in activities. These aspects of capacity building formed the crux of our training programme. It was a lack of available training in population-based cancer research for oncologists that motivated the programme’s creation. Didactic sessions were developed to build knowledge and skills in epidemiology, biostatistics, research ethics and regulation, data collection and management and sociocultural anthropology. Each of these sessions was led by an instructor with graduate-level training in public health or anthropology.

The trainee’s perceptions of their own research abilities were assessed by using a clinical research appraisal inventory. This tool, which was developed to assess clinician-scientists’ self-efficacy to perform clinical research,<sup>10</sup> has been used to evaluate training programmes in clinical research.<sup>11</sup> Between the initiation and end of our training programme, participants demonstrated substantial improvements in their self-perceived efficacy for study conceptualization, study planning and the ethical conduct of research (data not shown).

### Tools

The fourth and final level of the Potter–Brough model describes “performance capacity” – i.e. the availability of resources needed to complete activities. The best-trained clinician researchers cannot work effectively if the resources that are available fail to meet their needs. At this level of the model, the Cancer Control Research Training Institute needed to know if the tools required for our training programme – and those required to sustain any likely future training – were available.

#### Box 1. Summary of main lessons learnt

- A year-long training programme for clinicians could build useful cancer research capacity in low- and middle-income countries.
- Training in population-based research methods will enable low- or middle-income countries such as Guatemala to gather country-specific data.
- Once collected, such data can be used to assess – and guide policy for reducing – the burden of cancer-related disease and identify priority areas for cancer prevention and treatment.

Before our training programme, Washington University in Saint Louis was conducting relevant coursework and activities. For our programme, these were adapted to the Guatemalan perspective. Other components of the programme were developed from scratch. For example, sessions on database management and data collection tools were not only created specifically for the programme but also adapted during the programme – to satisfy the participants’ needs as they developed their own research projects.

At the end of our training programme, it seemed clear that the ability to gather data to further Guatemala’s cancer prevention and control efforts would still be very limited if no more of INCAN’s clinicians could be trained in the relevant research methods. To begin to address this problem, INCAN translated some of the educational materials used in the training programme into Spanish and incorporated them into residency training; purchased relevant textbooks for clinician use; and established a journal club so that research discussions could be incorporated into future training.

### Value-added benefits

During and after the training programme, various ancillary activities helped to build and solidify relationships that are likely to be critical to sustaining capacity for research training. In response to a dialogue initiated by the Cancer Control Research Training Institute, for example, annual cancer seminars were established in Guatemala. Each of these seminars has been built around a presentation by researchers from Washington University in Saint Louis. Although these meetings were originally planned only for INCAN’s clinicians, other clinicians from Guatemala as well as some of their counterparts from El Salvador, Honduras and Mexico, have attended recent seminars. One seminar has included a workshop on cancer pathology. At another, an

anthropologist from the United States – who had worked in Guatemala – led a workshop on qualitative research and cultural competence. Clinicians from both partners involved in the training programme have met with representatives from the *Liga Nacional Contra el Cáncer* and the Guatemalan Ministry of Health to discuss priorities for cancer prevention, control and care in Guatemala. By highlighting the Cancer Control Research Training Institute’s activities, the Guatemalan media have helped raise awareness among the Guatemalan people about the country’s cancer burden and the need to strengthen training in cancer research to address ground-level issues such as surveillance, prevention and quality of care.

### Current status

Since the end of our training programme, INCAN has established a research department and begun research collaborations with the United States National Cancer Institute, the Swiss Federal Technological Institute and the Nutrition Institute of Guatemala. Today, several of INCAN’s clinicians are engaged in research projects – on cervical and breast cancer and Mayan concepts of medicine and cancer – or, at least, applying for research grants. Most importantly, perhaps, INCAN’s administrators – in conjunction with the Guatemalan government, the International Agency for Research on Cancer, the Union for International Cancer Control and PAHO – are in the early stages of developing a national cancer registry. INCAN’s leadership credits the Cancer Control Research Training Institute with raising research interest and engaging the stakeholders needed to support the incorporation of research into INCAN’s activities.

### Lessons learnt

The main lessons learnt are summarized in **Box 1**. Participants in our training

programme gained confidence in their ability to conduct population health research and developed research protocols that have begun to address some of Guatemala's cancer-related needs. However, some challenges were recognized that must be addressed to sustain future training. One of these was language – all trainees had to be fluent in English, partly because it was hoped they would have opportunities to present their work in English at international venues. At the time of our training programme, the Cancer Control Research Training Institute had no teachers of English, even though proficiency in English in general – and particularly in the technical English used in research – was considered essential in the training programme. A similar training programme in Spanish would benefit a broader group of the clinicians at INCAN. Trainees cited the international travel included in the training programme as critical to developing international relationships and collaborations, as well

as to understanding the context in which partners worked. As such travel may not be financially sustainable in the future, the training of the next cohort may have to rely more heavily on Internet-based meetings and didactic sessions. Such online training has the advantage that it could easily be expanded to cover a large audience. Further funding will be needed to ensure that INCAN keeps up to date with resources such as software and texts. The employers of the trainees must provide the trainees with protected time for participation in training programmes and research.

## Conclusion

INCAN's Cancer Control Research Training Institute illustrates one approach to building capacity for cancer research, prevention and control in a low- or middle-income country such as Guatemala. By training local clinicians in research methods in population health, LMICs will be able to gather

country-specific data to assess disease burden, identify priority areas for prevention and treatment, and guide policy – a critical component to addressing the global burden of cancer.<sup>12</sup> The desired long-term outcomes specific to cancer in Guatemala include building systems to gather data for advocating for resources, guiding clinical practice, advocating for cancer prevention and control policies and monitoring the role of cancer in the health of the Guatemalan people. ■

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## ملخص

برنامج تدريبي لبناء القدرة في بحوث السرطان في البلدان المنخفضة والمتوسطة الدخل: النتائج من غواتيمالا  
 ومن ثم، فإن معهد INCAN يمثل مورداً لبناء القدرة في سياق توقي السرطان ومكافحته. التغييرات ذات الصلة قام المتدربون بصقل كفاءاتهم الذاتية في تصميم البحوث وإجرائها. وشملت الفوائد ذات القيمة المضافة إقامة حلقة تعليمية سنوية عن السرطان وورش عمل حول باثولوجيا السرطان والتحليل النوعي. وقام معهد INCAN في الآونة الأخيرة بإدراج بعض مكونات البرنامج في تدريب الإقامة التابع له وأنشأ إدارة بحثية. الدروس المستفادة يستطيع برنامج تدريبي للخبراء السريريين بناء القدرة في بحوث السرطان في البلدان المنخفضة والمتوسطة الدخل. وسوف يتيح التدريب على طرق البحث المستندة على السكان للبلدان مثل غواتيمالا جمع البيانات الخاصة بالبلد. وبمجرد جمع هذه البيانات، يمكن استخدامها لتقييم - عبء المرض المتصل بالسرطان وتوجيه السياسات للحد منه وتحديد مجالات الأولوية لتوقي السرطان وعلاجه.

المشكلة تركز غواتيمالا تحت عبء سرطان متزايد إلا أنها تفتقر إلى القدرة لتوقي السرطان ومكافحته وإجراء البحوث عليه. الأسلوب بالتعاون مع إحدى كليات الطب في الولايات المتحدة الأمريكية، تم إنشاء معهد تدريب على بحوث مكافحة السرطان متعدد التخصصات في Instituto de Cancerología (INCAN) في مدينة غواتيمالا. وقدم هذا المعهد برنامجاً تدريبياً لمدة عام إلى الخبراء السريريين ركز على طرق البحث في الصحة السكانية والأنثروبولوجيا الاجتماعية والاقتصادية. وتضمن البرنامج خبرات تعليمية في غواتيمالا والولايات المتحدة بالإضافة إلى التدريب التطبيقي الذي قام المشاركون من خلاله بوضع بروتوكولات بحثية تلبى احتياجات التعامل مع السرطان في غواتيمالا. المواقع المحلية رغم أن معهد INCAN هو مركز الإحالة والخدمات لمرضى السرطان في غواتيمالا، إلا أن إدارة المعهد تهتم كذلك بزيادة بحوث السرطان - مع تركيز على صحة السكان.

## 摘要

### 中低收入国家建立癌症研究能力的培训项目：危地马拉的研究结果

**问题** 危地马拉正在承受越来越沉重的癌症负担，并且缺乏癌症预防、控制和研究的能力。

**方法** 危地马拉市癌症研究所 (INCAN) 携手美国的一家医学院建立了一所多学科癌症控制研究培训机构。该机构为专攻人口健康和社会文化人类学研究方法的临床医生提供为期一年的培训计划。计划包括危地马拉和美国的的教学体验以及应用培训，其中参与者制定出针对危地马拉癌症需求的研究方案。

**当地状况** 虽然 INCAN 是危地马拉癌症病人转诊和服务的中心，但机构管理部门以人口健康为重点，对日益增加的癌症研究也很关注。INCAN 因此成为癌症预防和控制环境下能力构建的资源。

**相关变化** 受训者提高了设计和处理研究的自我效能。带来附加价值的益处包括建立癌症病理学和定性分析的年度癌症研讨会和讲习班。INCAN 最近将计划的一些组成部分融入住院医师培训并建立了一个研究部门。



**经验教训** 临床医生的培训项目可以在中低收入国家培养癌症研究的能力。以人口为基础的研究方法培训将使危地马拉等国家能够收集与国情相关的数据。这些

数据一经收集可以用来评估癌症相关疾病的负担以及减少负担的指导政策，并确定癌症预防和治疗的优先领域。

## Résumé

### Un programme de formation pour renforcer la capacité de recherche sur le cancer dans les pays à revenu faible et intermédiaire: résultats du Guatemala

**Problème** Le Guatemala connaît actuellement une charge accrue de morbidité liée au cancer, mais le pays n'a pas la capacité suffisante en matière de prévention, de suivi et de recherche pour lutter contre cette maladie.

**Approche** En partenariat avec une faculté de médecine située aux États-Unis d'Amérique, un institut multidisciplinaire de formation et de recherche dans la lutte contre le cancer a été créé à l'*Instituto de Cancerología* (INCAN) dans la ville de Guatemala. Cet institut a fourni un programme de formation d'un an aux cliniciens, qui mettait l'accent sur les méthodes de recherche dans le domaine de la santé de la population et de l'anthropologie socioculturelle. Ce programme incluait des expériences didactiques au Guatemala et aux États-Unis d'Amérique, ainsi qu'une formation pratique au cours de laquelle les participants ont développé des protocoles de recherche répondant aux besoins en matière de cancer du Guatemala.

**Environnement local** Bien que l'INCAN soit le point de référence et de service pour les patients atteints de cancer au Guatemala, l'administration de l'institut cherche également à augmenter la recherche sur le cancer en mettant l'accent sur la santé de la population. L'INCAN est donc une

ressource pour renforcer la capacité dans le contexte de la prévention et de la lutte contre le cancer.

**Changements significatifs** Les stagiaires ont augmenté leur propre efficacité en matière de conception et de conduite de la recherche. Les bénéfices à valeur ajoutée comprenaient l'instauration d'un séminaire annuel sur le cancer et d'ateliers de travail portant sur la pathologie du cancer et l'analyse qualitative. L'INCAN a récemment intégré certains éléments du programme dans la formation de ses internes et a créé un département de recherche.

**Leçons tirées** Un programme de formation pour cliniciens peut renforcer la capacité de recherche sur le cancer dans les pays à revenu faible et intermédiaire. La formation aux méthodes de recherche axées sur la population permettra aux pays tels que le Guatemala de recueillir des données spécifiques au pays. Une fois collectées, ces données peuvent être utilisées pour évaluer la charge de morbidité liée au cancer, pour orienter les politiques dans la lutte contre la maladie et pour identifier les zones prioritaires dans les domaines de la prévention et du traitement du cancer.

## Резюме

### Программа обучения для создания научно-исследовательского потенциала в области борьбы с раком в странах с низким и средним уровнями доходов: выводы на примере Гватемалы

**Проблема** Гватемала испытывает возрастающее бремя рака, но стране не хватает потенциала для проведения профилактики, контроля и исследований рака.

**Подход** В партнерстве с медицинской школой из США, в Гватемале при Институте канцерологии (INCAN) был основан междисциплинарный Институт по исследованиям и обучению методам борьбы с раком (Cancer Control Research Training Institute). Этот институт разработал и провел годичную программу обучения для врачей, направленную на методы исследования в областях состояния здоровья населения и социально-культурной антропологии. Программа включала в себя дидактический опыт Гватемалы и США, а также проводила обучение, в ходе которого участники разрабатывали научно-исследовательские протоколы, отражающие потребности борьбы с раком в Гватемале.

**Местные условия** Хотя Институт канцерологии (INCAN) является учреждением для направления и лечения больных раком в Гватемале, администрация института также заинтересована в расширении исследований в области рака – с акцентом на здоровье населения. Таким образом, INCAN представляет собой

ресурс для наращивания потенциала в области профилактики и борьбы с раком.

**Осуществленные перемены** Слушатели программы повысили свою эффективность в области разработки и проведения научных исследований. Дополнительным преимуществом явилась организация ежегодных теоретических и практических семинаров по раковым патологиям и качественному анализу. Институт канцерологии недавно включил некоторые из компонентов программы в собственные программы обучения и создал научно-исследовательский отдел.

**Выводы** Программа обучения врачей способствует созданию научно-исследовательского потенциала в области борьбы с раком в странах с низким и средним уровнями доходов. Обучение с использованием популяционных методов исследования позволит таким странам, как Гватемала, начать собирать данные в масштабах страны. Собранные данные могут быть использованы для оценки бремени связанных с раком заболеваний, выработки стратегии для их сокращения и определения приоритетных направлений для профилактики и лечения рака.

## Resumen

### Un programa de capacitación para aumentar la capacidad de investigación del cáncer en los países de bajos y medianos ingresos: hallazgos de Guatemala

**Situación** Guatemala tiene una incidencia de cáncer cada vez mayor, pero carece de la capacidad para la prevención, el control y la investigación del cáncer.

**Enfoque** En asociación con una escuela de medicina de Estados Unidos de América, se ha creado un instituto de investigación multidisciplinar para el control del cáncer en el Instituto de Cancerología (INCAN) de la

ciudad de Guatemala. Este instituto ofreció un programa de formación de un año a médicos que se especializaban en los métodos de investigación en materia de salud pública y antropología sociocultural. El programa incluía las experiencias didácticas en Guatemala y Estados Unidos, así como la formación aplicada en la cual los participantes desarrollaron protocolos de investigación que respondían a las necesidades de cáncer de Guatemala.

**Marco regional** Aunque INCAN es el punto de referencia y de servicios para los pacientes con cáncer de Guatemala, la administración del instituto también está interesada en aumentar la investigación del cáncer, centrándose en la salud pública. INCAN es un recurso para desarrollar la capacidad en el contexto de la prevención y el control del cáncer.

**Cambios importantes** Los participantes aumentaron su propia eficacia

en el diseño y la realización de la investigación. Los beneficios de valor añadido incluyeron el establecimiento de un seminario de cáncer anual y talleres sobre la patología del cáncer, así como un análisis cualitativo. Recientemente, INCAN ha incorporado algunos de los elementos del programa en su capacitación residencial y ha establecido un departamento de investigación.

**Lecciones aprendidas** Un programa de capacitación para los médicos puede aumentar la capacidad de investigación del cáncer en los países de bajos y medianos ingresos. La capacitación en los métodos de investigación basados en la población permitirá a países como Guatemala recopilar datos específicos de cada país. Tras obtener los datos, pueden utilizarse para evaluar la incidencia de las enfermedades relacionadas con el cáncer, orientar las políticas para reducirla e identificar las áreas prioritarias para la prevención y el tratamiento del cáncer.

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