

CANCER CONTROL 2020

CANCER CARE IN EMERGING HEALTH SYSTEMS



EDITOR-IN-CHIEF: **DR IAN MAGRATH**, PRESIDENT, INTERNATIONAL NETWORK FOR CANCER TREATMENT AND RESEARCH
COMMISSIONING EDITOR: **MARK LODGE**, DIRECTOR, INTERNATIONAL NETWORK
FOR CANCER TREATMENT AND RESEARCH UK

- GLOBAL CANCER INITIATIVES • REGIONAL REPORTS: AFRICA FOCUS
- SURVEY: COVID-19 AND LMIC CANCER CARE
 - SPECIAL REPORT: LONDON GLOBAL CANCER WEEK
 - CANCER PREVENTION AND TREATMENT • INCTR UPDATE

global health 
dynamics **INCTR**

PUBLISHED BY GLOBAL HEALTH DYNAMICS IN OFFICIAL ASSOCIATION WITH THE INTERNATIONAL NETWORK FOR CANCER TREATMENT AND RESEARCH

EDITOR-IN-CHIEF

DR IAN MAGRATH,
PRESIDENT, INTERNATIONAL NETWORK FOR CANCER
TREATMENT AND RESEARCH

COMMISSIONING EDITOR

MARK LODGE, DIRECTOR, INCTR UK
For editorial enquires including submissions contact:
mlodge@canet.org

EDITORIAL ADVISORY BOARD

Ali Saeed Al-Zahrani
Rajendra Badwe
Robert Burton
Sidnei Epelman
Hussein Khaled
Lorenzo Leocini
Twalib Ngoma
Max Parkin
Ama Rohatiner
Rengaswamy Sankaranarayanan
Aziza Shad
Richard Sullivan
Simon Sutcliffe

PUBLISHER

TIM PROBART
Contact details: tprobart@globalhealthdynamics.co.uk

For sponsorship and advertising contact:
cancercontrol@globalhealthdynamics.co.uk
or phone +44 (0) 7960 72 79 38

DESIGN

Marriott Graphics
www.smarriott.co.uk

COPY EDITOR

MADLINE PEARSON

CANCER CONTROL 2020

is published by Global Health Dynamics Limited
in official association with the International Network for
Cancer Treatment and Research

GLOBAL HEALTH DYNAMICS

20 Quayside, Woodbridge, Suffolk
IP12 1BH, UK
P: +44 1394 446023
www.globalhealthdynamics.co.uk
E: cancercontrol@globalhealthdynamics.co.uk

**INTERNATIONAL NETWORK FOR CANCER TREATMENT
AND RESEARCH**

Rue Engeland 642
B 1180 Brussels, Belgium
P: +32 2 373-9323
F: +32 2 373-9313
www.inctr.org

All rights are reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise without the permission of the Publisher.

The information contained in this publication is believed to be accurate at the time of manufacture. Whilst every care has been taken to ensure that the information is accurate, the Publisher and the International Network for Cancer Treatment and Research can accept no responsibility, legal or otherwise, for any errors or omissions or for changes to details given to the text or sponsored material. The views expressed in this publication are not necessarily those of the Publisher or of the International Network for Cancer Treatment and Research.

Application for reproduction should be made in writing to the Publisher.

Copyright © Global Health Dynamics 2020

ISBN 978-1-9160216-4-8

FIRST PUBLISHED 2020

Cover picture credit: INCTR

Acknowledgements

The Publisher and the International Network for Cancer Treatment and Research would like to thank the contributors, the Editorial Advisory Board, the peer-review panel and the Sanofi Espoir Foundation without whom *Cancer Control 2020* would not have been possible.

CONTENTS

05 Introduction **Dr Ian Magrath**, President, INCTR and **Tim Probart**, Publisher, Cancer Control

07 Cancer Control 2020 Survey: The impact of the COVID-19 pandemic on the care of cancer patients

GLOBAL CANCER INITIATIVES

12 Cancer and the ageing population: Lessons from palliative care

Rowena Tasker, Global Advocacy Manager, Knowledge, Advocacy and Policy Team; **Philip Martinez**, Knowledge, Advocacy and Policy Team and **Dr Sonali Johnson**, Head of Knowledge, Advocacy and Policy, Union for International Cancer Control (UICC)

17 Sponsored feature: My Child Matters: An initiative of the Sanofi Espoir Foundation

Valentine Leuenberger, **Laurence Bollack**, **Valérie Faillat** and **François Desbrandes**, Sanofi Espoir Foundation; and **Julia Challinor**, International Society of Paediatric Oncology (SIOP)

22 The case for collective Commonwealth action on cervical cancer

Professor Isaac F Adewole, Gynaecologic Oncology Unit, Department of Obstetrics & Gynaecology, College of Medicine, University of Ibadan, Nigeria and **Dr Ophira Ginsburg**, High-Risk Cancer Genetics Program, Perlmutter Cancer Center, School for Global Health, Department of Population Health, New York School of Medicine, New York, USA

27 The shifting global burden of cancer: Cancer Research UK's engagement with low- and middle-income countries

Bekki Field, Programme Lead, International Cancer Prevention, Cancer Research UK and **Caroline Mitchell**, Research Grants and Communications Officer, India-UK Cancer Research Initiative

31 Special report on the inaugural London Global Cancer Week

REGIONAL REPORTS: AFRICA FOCUS

38 Towards a reference centre for the diagnosis of childhood cancers in Dakar, Senegal

Professor Martine Raphaël, Vice-President, Alliance Mondiale Contre le Cancer (AMCC), France; **Professor Awa Toure**, Head of Haematology Laboratory, Aristide Le Dantec University Hospital, Cheikh Anta Diop University, Dakar, Senegal; **Professor Cherif Dial**, pathologist, Idrissa Pouye de Grand Yoff General Hospital, Cheikh Anta Diop University, Dakar, Senegal; **Professor Abibatou Sall**, MD, PhD, Haematologist, Dalal Jamm University Hospital, Cheikh Anta Diop University, Dakar, Senegal; **Dr Fatou Bintou Diagne**, paediatric oncologist, Aristide Le Dantec University Hospital, Cheikh Anta Diop University, Dakar, Senegal; **Dr Fatimata Bintou Sall**, haematologist, Aristide Le Dantec University Hospital, Cheikh Anta Diop University, Dakar, Senegal; **Professor Aurore Coulomb**, Head of the Pathology Department, Armand Trousseau/La Roche Guyon University Hospital, AP-HP, Sorbonne University, Paris, France; **Dr Elisabeth Auberger**, pathologist, Simone Veil Hospital, Eaubonne, France; and **Dr François Desbrandes**, Head of the "My Child matters" childhood cancer programme, Sanofi Espoir Foundation in Paris, France

42 Understanding breast cancer survivorship in Tanzania

Dr Nazima J Dharsee, Ocean Road Cancer Institute, Dar es Salaam, Tanzania and **Professor Theresa Wiseman**, The Royal Marsden NHS Foundation Trust, University of Southampton, UK

46 Cancer control in sub-Saharan Africa and its impact on health systems strengthening: A case study from Ghana

Dr Beatrice Wiafe Addai, Chief Executive Officer and Senior Medical Officer, Peace and Love Hospitals in Accra and Kumasi, Ghana

49 Diagnostic imaging challenges to the poor on the long road to the cancer centre

Dr Elizabeth Joekes, Co-founding Director, Worldwide Radiology and Consultant Radiologist, Liverpool University Hospitals Foundation Trust, UK, and **Dr Sam Kampondeni**, Neuroradiologist, Queen Elizabeth Central Hospital, Blantyre, Malawi

53 Using the African Digital Health Library for cancer control: Dissemination of African cancer research output

Christine Wamunyima Kanyengo, Librarian, University of Zambia; **Dr Grace Ada Ajuwon**, Principal Librarian, E Latunde Odeku Medical Library, College of Medicine, University of Ibadan, Nigeria; **Abdrahamane Anne**, Medical Librarian, Faculty of Medicine, University of Bamako, Mali; **Muziringa Masimba**, Health Librarian, formerly at University of Zimbabwe; Nancy Kamau university librarian, Kenya Methodist University, Kenya; **Justin Maranga Merande**, Head of Electronic Resource Training, College of Health Sciences Library, University of Nairobi Library, Kenya; **Nason Bimbe**, software developer; **Mercy Wamunyima Monde** Librarian, School of Medicine, University of Zambia; **Celine Maluma Mwafuilwa**, Librarian, Medical Library, University of Zambia; **Mark Lodge**, Executive Director, International Network for Cancer Treatment and Research UK; **Becky Lyon**; **Julia Royall**, Principal Investigator, African Digital Health Library

CANCER PREVENTION AND TREATMENT

60 Lowering the burden of cancer in a middle-income country: The idealist versus the pragmatist approach

Dr Feisul Idzwan Mustapha and **Dr Arunah Chandran**, Disease Control Division, Ministry of Health Malaysia, Wilayah Persekutuan Putrajaya, Malaysia

66 Evolution of the role of the pharmacist in preventing cervical cancer in low- and middle-income countries

Michelle Asiedu-Danso, Department of Pharmacy Practice and Clinical Pharmacy, School of Pharmacy, University of Ghana, Accra, Ghana; **Kwame Pepreh-Boaitey**, Pharmaceutical Society of Ghana; **Chloe Tuck**, School of Health and Related Research, University of Sheffield, and Commonwealth Pharmacists' Association, London, UK; and **Victoria Rutter**, Commonwealth Pharmacists' Association, London, UK

71 Why an understanding of anthropology is important for cancer control

Carlo Caduff, Reader in Global Health and Social Medicine, King's College London, UK

INCTR UPDATE

74 Mission, organization and achievements

77 INCTR Branches

78 INCTR Governing Council and partner institutions in developing countries

78 Partners: Past and present

Welcome to Cancer Control 2020

This eighth edition of Cancer Control comes at a time when global health issues could not be more important and visible; even taking precedence over economics as a key driver of government and individual's activities. The COVID-19 pandemic has struck most countries with devastating effect and has led to cancer specialists and facilities being repurposed to contain the new threat. It remains to be seen what long-term impact this will have on cancer care in low- to middle-income countries, but even in the short-term much damage has been done already.

In *Cancer Control 2020*, we start to understand what has happened from the cancer perspective with a global survey of our colleagues on the impact of COVID-19, and here we publish a selection of anecdotal comments for a quick first insight. Each contributor has something different to say: in Nigeria there is a rise in costs as PPE is required; in The Philippines and Ghana lockdowns have caused disruptions and restricted patients' and caregivers' freedom to travel; in Russia quarantining has robbed the cancer services of specialists and nurses; and all our contributors speak of the distress caused to patients.

In the next edition of *Cancer Control*, we shall go deeper into how COVID-19 has impacted on cancer services in LMICs and what steps are being taken to get back on track – which promises to be quite a challenge, and one where shared experiences will be crucial.

In this edition, we can see something of this spirit of cooperation and collaboration in the global context as we hear from the International Union for Cancer Control (UICC) on the important issue of how ageing populations are causing an upsurge in cancer – an issue that has not had the recognition it should. The My Child Matters programme of the Sanofi Espoir Foundation sets out their collaboration philosophy and new initiatives; as does Cancer Research UK, whose global approach includes tobacco control, science partnerships and cervical cancer prevention. The latter is also a major concern of the Commonwealth, who are also strong on collaboration.

Last year, *Cancer Control* was media partner to the inaugural London Global Cancer Week, which brought together a global audience attending multiple events in the UK's capital. We have included a special report on the occasion in this edition.

Our Regional Reports section focuses on Africa this year, with the Alliance Mondiale Contre Le Cancer writing about a new cancer reference centre in Senegal that is being created; we look at breast cancer survivorship in Tanzania; a partnership model in Ghana between a private hospital and an NGO that is working to great effect; the challenges facing diagnostic imaging for those in regions with few resources; and we catch up with the African Digital Health Library whose librarians are joining up university medical libraries across

countries and languages to liberate access to global and local medical content.

We share an inspiring article from two members of Malaysia's Ministry of Health on how they have used a pragmatic approach, rather than an idealist one, to successfully lower the cancer burden in their country. We also highlight the evolving role that pharmacists are playing in cervical cancer prevention, and we learn from social science how anthropology can help formulate better, more considered strategies for cancer care.

Partnerships, collaborations, a global approach to problems, and sharing come through every article in this edition and we hope that you will not only find something of use, but also be motivated to find collaborative ways to work together in these difficult times. We would be delighted to have your feedback at cancercontrol@globalhealthdynamics.co.uk. Please visit our website www.cancercontrol.info for updates and also to find out more information about INCTR and its programmes, as well as how to join. ■

Dr Ian Magrath, Editor-in-Chief, Cancer Control and President, International Network for Cancer Treatment and Research

Tim Probart, MA, Publisher, Cancer Control and CEO, Global Health Dynamics

CANCER CONTROL 2020

CANCER CARE IN EMERGING HEALTH SYSTEMS



EDITOR-IN-CHIEF: **DR IAN MAGRATH**, PRESIDENT, INTERNATIONAL NETWORK FOR CANCER TREATMENT AND RESEARCH
COMMISSIONING EDITOR: **MARK LODGE**, DIRECTOR, INTERNATIONAL NETWORK FOR CANCER TREATMENT AND RESEARCH UK

- GLOBAL CANCER INITIATIVES • REGIONAL REPORTS: AFRICA FOCUS
- SURVEY: COVID-19 AND LMIC CANCER CARE
- SPECIAL REPORT: LONDON GLOBAL CANCER WEEK
- CANCER PREVENTION AND TREATMENT • INCTR UPDATE



PUBLISHED BY GLOBAL HEALTH DYNAMICS IN OFFICIAL ASSOCIATION WITH THE INTERNATIONAL NETWORK FOR CANCER TREATMENT AND RESEARCH

CANCER CONTROL 2017

CANCER CARE IN EMERGING HEALTH SYSTEMS



EDITOR-IN-CHIEF: **DR IAN MAGRATH**, PRESIDENT, INTERNATIONAL NETWORK FOR CANCER TREATMENT AND RESEARCH

- SURVEY • CANCER CONTROL ISSUES • CERVICAL CANCER
- REGIONAL INITIATIVES • PAEDIATRIC CANCER • INCTR



PUBLISHED IN OFFICIAL ASSOCIATION WITH THE INTERNATIONAL NETWORK FOR CANCER TREATMENT AND RESEARCH

CANCER CONTROL 2015

CANCER CARE IN EMERGING HEALTH SYSTEMS



EDITOR-IN-CHIEF: **DR IAN MAGRATH**, PRESIDENT, INTERNATIONAL NETWORK FOR CANCER TREATMENT AND RESEARCH
FOREWORD BY **DR SARA KHAN**, REGIONAL DIRECTOR FOR THE EASTERN MEDITERRANEAN REGION

- CANCER CONTROL PLANNING • CANCER MANAGEMENT AND EDUCATION
- DISEASE-SPECIFIC CANCER CONTROL • PAEDIATRIC CANCER
- REGIONAL INITIATIVES



PUBLISHED IN OFFICIAL ASSOCIATION WITH THE INTERNATIONAL NETWORK FOR CANCER TREATMENT AND RESEARCH

CANCER CONTROL 2014

CANCER CARE IN EMERGING HEALTH SYSTEMS

EDITOR-IN-CHIEF: **DR IAN MAGRATH**, PRESIDENT, INTERNATIONAL NETWORK FOR CANCER TREATMENT AND RESEARCH
FOREWORD BY **DR MARGARET CHAN**, DIRECTOR GENERAL, WORLD HEALTH ORGANIZATION



- GLOBAL CANCER POLICY-MAKING • RISK FACTORS • EPIDEMIOLOGY
- EARLY DETECTION • TREATMENT • PALLIATIVE CARE • PAEDIATRIC CANCERS
- REGIONAL INITIATIVES • ADVOCACY • KNOWLEDGE MANAGEMENT



PUBLISHED IN OFFICIAL ASSOCIATION WITH THE INTERNATIONAL NETWORK FOR CANCER TREATMENT AND RESEARCH

To purchase further copies or to advertise
or sponsor Cancer Control please visit
www.cancercontrol.info
or email **cancercontrol@globalhealthdynamics.co.uk**
or call **+44 1394 446023**

Cancer Control 2020 Survey: The impact of the COVID-19 pandemic on the care of cancer patients

In October 2020, *Cancer Control* invited colleagues to describe briefly how COVID-19 had affected cancer care in their countries to date. We thank everybody who was able to contribute and offer this selection of the responses we received. In future editions of *Cancer Control*, we will take a deeper look at the impact of COVID-19 on cancer care in low- and middle-income countries and how best to mitigate its impact.

AFRICA

ETHIOPIA



Zelalem Desalegn, BSc, MSc, Assistant Professor of Medical Microbiology, School of Medicine, College of Health Sciences, Addis Ababa University, Ethiopia

“Though the burden of the COVID-19 pandemic is not happening as predicted in Ethiopia, it is troubling the healthcare system. In Ethiopia, there is limited infrastructure, scarce cancer care centres, and few established satellite cancer treatment centres. On top of this, partial restriction and cancellation of some non-essential services hit hard the provisions of routine services in the healthcare setting for cancer patients.”

GHANA



Naomi Oyoe Ohene Oti, MPH, BSN, OCN, FWAC, Vice-President, Nursing, African

Organization for Research and Training in Cancer (AORTIC)

“COVID-19 has had a lot of impact on cancer care. Employers had to put measures in place to protect staff and patients which called for more resources. Also there were delays in cancer treatment and ongoing oncology care. Care providers were faced with ethical issues which affected their mental wellbeing.”

Verna DNK Vanderpuye, MBCHB, FWACS, FGCP,

Consultant Radiation Oncologist, National Center for Radiotherapy Oncology and Nuclear Medicine, Korle Bu Teaching Hospital, Accra, Ghana and **Naa Adorkor Aryetey**, Specialist Radiation Oncologist, Korle-Bu Teaching Hospital, Accra, Ghana

“SARS-COVID-19 has changed our practices. Accra and Kumasi, home to all the radiotherapy facilities in the country, were labelled epicentres and subjected to a two-week full lockdown on 15 March 2020. Cancer care was not spared from interruptions. The psychological distress amongst patients

and clinicians was rife. Following the easing of restrictions, WhatsApp platforms and the REDBIRD app were adopted for reviewing patients receiving chemotherapy, refill medication, rescheduling appointments to limit patient numbers and monitor staff and patient risk respectively. Radiotherapy treatments were not disrupted. Shift work increased workforce burnout, whilst patients experienced long waiting times from observing mandatory COVID-19 protocols. The Sweden Ghana Cancer Center, a private facility, bore the brunt of the travel restrictions which limited patients from neighbouring countries gaining access; many were also unable to leave Ghana. Online consultations gained a footing. Many of these adaptations currently remain in place. Land and sea borders remain closed, but with less than 400 active COVID-19 cases, many contemplate a return to normality. This pandemic reveals some silver linings to overcome non-essential clinical pathways in the cancer care continuum, especially for LMICs.”

KENYA



Dr Mohammed Ezzi, Medical Oncologist, University of Nairobi, Kenya

“The government’s one-size-fits-all COVID-19 containment strategy failed to factor in the needs of cancer patients who require continuous medical care. The cancer facilities are open only for a few hours daily. It disrupted care for patients who need to travel to urban areas to continue their care.”

NIGERIA



Professor Isaac F Adewole, Gynaecologic Oncology Unit, Department of Obstetrics and Gynaecology, College of Medicine, University of Ibadan, Nigeria

“The COVID-19 pandemic grounded several global activities including the provision of healthcare services to people with chronic conditions such as cancer. In Nigeria, the COVID-19 pandemic made a significant impact on cancer care in different

aspects:

- ➔ Disruption of access to care – patients on treatment (both chemotherapy and radiotherapy) had their treatment skipped, while surgeries were postponed because of the lockdown and curfew.
- ➔ High cost of care – cost of care skyrocketed especially with the need to do COVID-19 tests and also to procure additional safeguarding materials such as facemasks.
- ➔ Cancer screening activities were suspended – most organizations offering screening services had to close down or suspend activities in response to measures being taken to control the pandemic.
- ➔ Refusal to visit hospitals – many people refused to visit hospitals to continue their care because of fear of contracting the virus, especially from healthcare providers, and the worsening clinical status.
- ➔ Shift in focus – the political class and even health providers have momentarily shifted focus away from noncommunicable diseases and concentrate all their attention on finding ways of managing the pandemic.”

Zainab Shinkafi-Bagudu Zbagudu, *Medicad Cancer Foundation, Nigeria*

“With a population of over 200 million, Nigeria’s 14 cancer care centres are a significant distance from most patients. The restricted movement brought on by COVID-19 meant cancer patients could not access treatment. This reality was further compounded by limited availability and the high cost of PPE at the all facilities.”

SOUTH AFRICA



Linda Rogers, MBChB (UCT), FCOG (SA), MMed (UCT), *Senior Consultant, University of Cape Town, South Africa*

“Our aim: provision of holistic care for gynaecological cancer patients, despite oncology staff also looking after COVID-19 patients and theatre-time shortages. The risk of not treating cancers was balanced against the risks of SARS-COV2 to patients and staff. What is left? Long waiting lists, and suffering women requiring palliation.”

ASIA

MALAYSIA



Dr Saunthari Somasundram, *President, National Cancer Society, Malaysia (NCSM)*

“What we thought was the worst – delay of cancer treatment, care and support – are actually only the short-term effects of COVID-19. It’s insidious, it’s only just starting, and it’s death by a thousand cuts: each wave of the pandemic takes away something from cancer care permanently; whether it’s funds,

budget, or resources.”

THE PHILIPPINES



Jimmy A Billod, MD, MHcA, *Gynecologic Oncologist, Baguio General Hospital and Medical Center, Baguio City, The Philippines*

“Our cancer centre caters for patients from the region and nearby provinces. Community lockdowns, border restrictions, reduction in accommodation and/or schedules, meticulous screening protocols prior to and in between treatments caused an upsetting consequence in the care of patients. Delay in the diagnosis and treatments; and interruption of follow-ups engendered progression of the disease and stress to patients and their families.”

CARIBBEAN

PAN-REGIONAL

A Caribbean cancer patient with kind permission of the *Healthy Caribbean Coalition*

“Cancer patients in the Caribbean often have to be innovative because of our region’s limited resources. Perhaps this increases our resilience in dealing with COVID-19. But the isolation, supposed to keep us safe, will have lasting impacts. Usually, we count on the community to help us with our diagnosis. Now that same community is the threat.”

SAINT LUCIA



Owen O Gabriel, MD, DM, *Consultant Oncologist and Head of Department, Owen King EU Memorial Hospital, Saint Lucia, West Indies*

“Cancer care has always been the most significant burden on our healthcare system. The COVID-19 pandemic has further aggravated already existing deep financial and human resource constraints. Patients could not obtain surgical or chemotherapy services locally. Radiation therapy and other tertiary care could no longer be accessed overseas.”

EASTERN EUROPE

RUSSIAN FEDERATION



L Korolenkova, MD, PhD, *Senior Researcher, National Oncological Centre, Moscow and S Rogovskaya, MD, PhD*, *President of the Russian Association for Genital infections and Neoplasia (RAGIN)*

“The COVID-19 pandemic in Russia has had a negative impact on the management of cancer patients. There are two main reasons: the susceptibility of patients to coronavirus per se and delays in treatment, especially radiation or chemotherapy, due to isolation requirements. The increase of the incidence of COVID-19 in oncologists has led to the closure of oncology units due to quarantining. Also, the need for patients to

perform COVID-19-tests before hospitalization and collect documents from home can be a burden.”

LATIN AMERICA

PAN-REGIONAL

Eduardo L Cazap MD, PhD, FASCO, President, Latin-American and Caribbean Society of Medical Oncology (SLACOM); Past President, Union for International Cancer Control (UICC); Emeritus Professor, Latin American School of Oncology (ELO)

“Our collective regional prioritization of COVID-19 and implementation of physical distancing as an intervention strategy has impaired cancer health providers’ functioning, specifically by postponing cancer screening, in-person consultations, and control tests, as well as limiting treatments that might result in significant risk of infectious complications or require critical care. The coronavirus pandemic provides an opportunity for society to act in solidarity and find in this crisis the impetus to achieve the Sustainable Development Goals: Goals # 3 (Health and well-being), #110 (Reducing inequalities) and # 17 (Developing alliances to accomplish the proposed objectives).”

COLOMBIA



Gloria I Sanchez, MSc, PhD, Profesora titular
Coordinadora Grupo Infección y Cáncer, Facultad
de Medicina, Universidad de Antioquia, Medellín, Colombia

“Cervical, breast, colon and prostate cancer screening has decreased by 80% in Colombia.”

PERU



Tatiana Vidaurre, MD, Medical Oncologist,
Instituto de Enfermedades Neoplásicas (INEN),
Lima, Peru

“Blood transfusions for cancer patients were critically affected by the COVID-19 pandemic in Peru. Voluntary blood donation has been reduced at the Peruvian National Cancer Institute (INEN). Levels have fallen from 130 to 50 units/day and the blood bank stock was reduced from 350 units/day to under the critical stock limit of 150 units/day during the mandatory quarantine.”

MIDDLE EAST

EGYPT



Dr Mahmoud Motaz Elzembely, MSc, MD,
Lecturer in Paediatric Oncology, South Egypt
Cancer Institute, Assiut University, Egypt

“The COVID-19 pandemic negatively affected paediatric cancer care in my centre. Negative impacts were a shortage

of medical personnel, delay in diagnosis, delay in treatment for children who had COVID-19, decreasing the number of children allowed within single a room with a consequent decrease in department capacity and a chemotherapy shortage.”

Ahmed Elzawawy, MD, Professor of Clinical Oncology, Suez Canal University, Ismailia and Port Said, Egypt

“Until this month (October 2020), there was a higher incidence of COVID-19 in Egypt and the Republic of South Africa than the general picture in Africa, but the level is still far below that prevalent in United States, United Kingdom and Italy. In Egypt, in the beginning there was a delay in most cancer diagnostic and treatment services. However, recently the picture has improved with modifications of protocols of investigations and treatment, e.g., hypofractionated radiotherapy and outpatient chemotherapy. In The Global Health Catalyst win-win movement, we suggest that in the world, particularly in LMICs and Africa, these scientific modifications could lessen the negative economic impact on expenditure for access to cancer care after the pandemic.”

Dr Khaled Kamal, Director of the Mersal Oncology Center, Egypt

“In Egypt, due to the limited partial lockdown, cancer care was not majorly affected by the pandemic. The main effect was seen on treatment decisions: more spaced regimens, hypofractionated radiotherapy protocols and more prophylactic G-CSF use. Due to economic effect, funds to NGOs were affected, so affecting cancer treatment”.

LEBANON



Hana Chaar Choueib, General Manager,
Children’s Cancer Center of Lebanon (CCCL)

“As a leading regional centre pioneering the treatment and care of kids and adolescents with cancer in Lebanon, the Children’s Cancer Center of Lebanon (CCCL) has witnessed many challenges as a result of the coronavirus outbreak in the country and across the globe. In terms of patient treatment and care, and to mitigate all risks of infection, we had to make a major change in the psychosocial support offered to patients where no in-facility entertainment activities were allowed for patients during treatment. Therefore, we initiated a virtual series of entertainment and wellness sessions for patients who could access them through their phones or tablets at any time they wanted. More time and effort were spent on promoting awareness to patients and families to abide by the hygiene measures to protect themselves. Moreover, extra costs were incurred to supply the protective gear and equipment needed for patients, parents, as well as staff; in addition to those for testing when needed. Being dependent on public donations to

sustain the life-saving mission of the CCCL, the coronavirus outbreak resulted in the cancellation of several planned fundraising and awareness-raising events. Nevertheless, we were able to adapt and initiate a variety of online and virtual activities to meet our organization's obligations and to continue offering services to kids with cancer in Lebanon. Cancer doesn't wait, and indeed the CCCL did not! Despite the many challenges coronavirus has caused, we ensured that childhood cancer patients still have access to adequate treatments and remain safe all through their treatment. "

SOUTH ASIA

INDIA



Bhawna Sirohi, Consultant Medical Oncologist,
Apollo Proton Cancer Centre, Chennai, India

"Hospital resources have been either completely diverted to coronavirus treatment, with cancer OPDs and day-care chemotherapy beds closed down, or the actual capacity reduced to prioritize coronavirus patients. A culture of fear has decreased outpatient attendance of new cancer cases by 70% to 80%. A cancer crisis is looming ahead."

Dr Gayatri Palat, MBBS, DNB, Associate Professor, Pain and Palliative Medicine, MNJ Institute of Oncology and Regional Cancer Center, Hyderabad, India

"Meeting the challenges of delivering palliative care posed by COVID-19 and lockdowns in Hyderabad does not pause due to pandemics or lockdowns. The current pandemic and the subsequent lockdowns resulted in cancer treatment getting disrupted for many, impacting on their survival, increased suffering and the need for palliative care. The local NGO, Pain Relief and Palliative Care Society, Hyderabad, supported by Two Worlds Cancer Collaboration-INCTR Canada, rose to this challenge by ensuring palliative care services continued uninterrupted looking after these patients. This could be achieved by taking steps such as establishing protocols, holding regular educative sessions by ECHO to remove apprehensions amongst staff and to teach about the PPE, hand hygiene and social distancing, ensuring sufficient PPE and virtual care."

Global Cancer Initiatives

12 Cancer and the ageing population: Lessons from palliative care

Rowena Tasker, Global Advocacy Manager, Knowledge, Advocacy and Policy Team; **Philip Martinez**, Knowledge, Advocacy and Policy Team and **Dr Sonali Johnson**, Head of Knowledge, Advocacy and Policy, Union for International Cancer Control (UICC)

17 Sponsored feature: My Child Matters: An initiative of the Sanofi Espoir Foundation

Valentine Leuenberger, **Laurence Bollack**, **Valérie Faillat** and **François Desbrandes**, Sanofi Espoir Foundation; and **Julia Challinor**, International Society of Paediatric Oncology (SIOP)

22 The case for collective Commonwealth action on cervical cancer

Professor Isaac F Adewole, Gynaecologic Oncology Unit, Department of Obstetrics & Gynaecology, College of Medicine, University of Ibadan, Nigeria and **Dr Ophira Ginsburg**, High-Risk Cancer Genetics Program, Perlmutter Cancer Center, School for Global Health, Department of Population Health, New York School of Medicine, New York, USA

27 The shifting global burden of cancer: Cancer Research UK's engagement with low- and middle-income countries

Bekki Field, Programme Lead, International Cancer Prevention, Cancer Research UK and **Caroline Mitchell**, Research Grants and Communications Officer, India-UK Cancer Research Initiative

31 Special report on the inaugural London Global Cancer Week

Cancer and the ageing population: Lessons from palliative care

Rowena Tasker (top left), Global Advocacy Manager, Knowledge, Advocacy and Policy Team; **Philip Martinez** (top right), Knowledge, Advocacy and Policy Team and **Dr Sonali Johnson** (bottom), Head of Knowledge, Advocacy and Policy, Union for International Cancer Control (UICC)



As the global population experiences a “longevity revolution” health systems around the world will need to respond to a rapidly increasing number of geriatric patients, yet few of these health systems appear prepared to respond to the unique needs of this population. Exploring the approach adopted by the palliative health community can help understand what opportunities this model might afford as we work to scale-up patient-centred, participatory care for older people with cancer.

Globally, there is a “longevity revolution” taking place in which the world’s population is ageing rapidly. There are currently over 703 million people worldwide above the age of 65 (1) years equating to 9.1% of the global population, and estimates suggest that the proportion of the population over the age of 65 is expected to rise to 15.9% (1.5 billion) by 2050 (1). The fastest growth is likely to be seen across the least developed countries, where the population of over 65s is projected to grow from 37 million in 2019 to 120 million in 2050 (1).

These demographic changes will have serious implications for health systems, particularly in responding to the rising burden of cancer and other noncommunicable diseases. Cancer is more prevalent in older adults, with cases amongst the over 65s accounting for over 50% of the global cancer burden (2), and are often detected at a more advanced stage. When combined with the unique challenges associated with the management of cancer in older people, this growth necessitates focused attention on older populations within cancer control policy and planning. However, current evidence suggests there are limited programmes and services in place to respond the needs of this population (3).

Addressing cancer and ageing will require engagement and support from across the cancer community to improve the comprehensiveness of care for cancer in older people. A comprehensive discussion of global priorities for geriatric oncology has recently been put forward by the International Society of Geriatric Oncology (SIOG) and outlines priorities for the global advancement of cancer care in older adults (4). In this article, we explore what the cancer community could

learn from approaches taken in palliative care that could inform efforts to increase access to multidisciplinary, patient-centred oncogeriatric care. We wish to emphasize that this is not a suggestion that older patients with cancer should only be offered palliative care services. Rather, we have sought to better understand what we can learn from the palliative care model as an essential component of comprehensive cancer care, and one which also emphasizes the importance of addressing the needs of a key vulnerable group.

Challenges facing geriatric oncology

Geriatric oncology is a comparatively recent branch of oncology that emphasizes the needs of older people. Its goal is to improve outcomes for older patients with cancer, recognizing and responding to the variable health status of these individuals. It seeks to establish patient-centred responses, using tools like comprehensive geriatric assessments (CGAs) to shape and prioritize multidisciplinary treatment.

A large part of the research to date has assessed the extent to which health systems are responding to the needs of older patients with cancer, with a particular focus on maintaining their quality of life and functional capacities. The literature documents a number of successes, including the development of patient-centred treatment tools, guidelines to improve the management of comorbidities, creation of multidisciplinary teams, and research to define appropriate indicators and metrics for success (5). It also identifies a series of challenges that are limiting the introduction, scale-up and uptake of geriatric oncology services that span the spectrum of cancer control, an overview of which are contained in Table 1.

Table 1: Key challenges facing geriatric oncology

Awareness	<ul style="list-style-type: none"> ➔ Poor awareness of the signs and symptoms of common cancer types amongst older people ➔ Limited awareness of the burden of cancer on older populations amongst political leaders, local communities, the media and the medical community ➔ Misinformation amongst political leaders, local communities, the media and the medical community around the ability to successfully treat or manage cancer
Detection and diagnosis	<ul style="list-style-type: none"> ➔ Limited capacities and use of comprehensive geriatric assessments to help shape and inform treatment pathways for older patients ➔ Uneven use of additional tools to screen, assess and refer older patients
Treatment and care	<ul style="list-style-type: none"> ➔ Poor national development/integration of guidelines for the assessment and treatment of older people with cancer ➔ Limited capacities to manage patients with multiple morbidities ➔ Limited inclusion/support of family caregivers tending to patients outside of inpatient/outpatient settings
Health system integration	<ul style="list-style-type: none"> ➔ Limited integration of training in geriatric oncology within core medical and nursing training ➔ Global shortage of geriatric specialists to support a multidisciplinary treatment approach ➔ Limited financial and other protection measures for older patients with cancer ➔ Limited availability of geriatric oncology clinics, particularly in low- and middle-income countries (LMICs) ➔ Variable integration of geriatric services within national health system and/or cancer planning
Research	<ul style="list-style-type: none"> ➔ Poor integration of older patients into clinical trials, which reduces their relevance ➔ Limited basic and translational research into the needs of older patients with cancer ➔ Limited data on equitable access to services (including treatment and other forms of care) ➔ Limited data on the investment-case for geriatric service

Responding to the challenges set out above will require the engagement and support of the cancer and broader health community to reform current health systems. Many of these hurdles are not new, and there are numerous different models that we can consider when thinking through how progress could be made. Given its focus on supporting the strengthening of health systems to deliver quality care, we see several interesting connections between the approach used by the palliative care community and the goals of the geriatric cancer movement. Moreover, palliative care is an essential cancer service and part of a cost-effective and integrated approach which will form an important pillar of all geriatric cancer services (6).

Scaling-up coordinated geriatric care: Learning from approaches to palliative care

Palliative care is a holistic approach that seeks to improve the quality of life of patients and their families facing life-threatening illness from the moment of diagnosis (7). It is dependent on the early identification and assessment of conditions, and responds using multidisciplinary teams to treat pain and other problems, be they physical, psychosocial or spiritual, and should not be reduced down to solely end-of-life care (8). It provides an interesting patient-centred model which, in its optimal form, coordinates expertise from across disciplines to deliver a plan that is shaped around the needs and preferences of the patient. While many countries are struggling to deliver this universally, and there is an urgent need to scale-up access, particularly in LMICs; several of the approaches used in palliative care could help inform discussions, planning and practices in the scale-up of oncogeriatric care.

Comprehensive care assessments

The first of these is a focus on developing patient-centred care through the use of comprehensive care assessments to shape care plans and referrals. The use of comprehensive geriatric assessments (CGAs) to develop tailored treatment plans, based on the stage of disease and capacities of patients' is central to geriatric oncology. These assessments gather information not routinely captured in oncology assessments and have been found to increase the effectiveness, efficiency and quality of care. In Sweden, the use of geriatric assessments was found to both increase the cost-effectiveness of care and preserve patients' physical fitness after hospital discharge (9, 10). Likewise, effective palliative care is centred on a robust assessment of patient needs and preferences. The World Health Organization's (WHO) guidelines on the management of cancer pain call on all countries to make use of assessments as a starting point for action. In recent years, there has been extensive work to develop new tools to streamline this assessment process and thereby expand the settings in which assessments can take place and improve their applicability. Conversely, the literature indicates that the complexity of undertaking CGAs has limited their use (11), in turn suggesting that there is a need for accelerated work to refine these tools and complement them with additional tests in order to scale-up the use of CGAs across countries and healthcare settings (12).

Inclusive multidisciplinary tumour boards

Following an assessment, the second approach focuses on establishing multidisciplinary support teams to deliver care in a timely and coordinated manner. Palliative care,

where implemented fully, draws on the expertise of multiple professions and there are strong examples of countries across different income levels making progress in coordinating multidisciplinary palliative care for older populations. In the context of health budget cuts, Edmonton, Canada, developed a comprehensive palliative care service consisting of family physicians, home care, hospice, a tertiary palliative care unit, and consulting services. The focus was on building a patient-centred system and facilitating easy and quick referral through to other levels of care as needed, to increase access and minimize the use of high-cost emergency services (13). In India, the development of palliative care services has seen significant localized health system reforms to establish a network of home-based care practitioners who can draw on the services of multidisciplinary collaborations to meet patient needs (14). In oncogeriatrics, tumour boards are the primary tool for multidisciplinary collaboration and the inclusion of geriatricians is an essential quality criteria; however poor engagement or availability of geriatricians has limited their systematic use. A focus on establishing mechanisms and building stronger collaborations between specialists and levels of the health system is essential, and has been a success factor in France, where networks for geriatric cancer centres have been established, but the role of geriatricians in the management of patients is still variable (15). What this suggests, however, is that integration is feasible and has the potential to increase the quality and financial efficiency of care, even amid challenging economic conditions.

Education and training

A final approach where there are fruitful parallels is in the strong focus on improving public awareness and increasing skills to deliver palliative care services. These can be broadly grouped under the heading of educational activities, which include communication and advocacy. Using additional training to improve clinical skills and retain palliative care staff has been central to the development of palliative care services, and there are several excellent examples from India, Uganda and Kenya. Responding to the shortage of trained health workers in Kathmandu, Nepal, a short course in palliative care was established to train nurses to deliver home-based palliative care in 2016. Looking ahead, work is being undertaken to support the integration of these nurses into the city and regional health systems to improve referrals and use of their skills (16). Given the global shortage of geriatric oncology training, the use of in-service and other training courses provides an interesting template which organizations like SIOG and others are exploring, including potential synergies with palliative care competencies (17). This is being conducted

alongside advocacy for the inclusion of geriatric oncology in core medical and nursing curricula (4).

In several countries, formal education of the health workforce has been supplemented with culturally relevant community-oriented educational initiatives, and collaboration with older people has helped reduce stigma and misinformation. In Uganda, a combination of media outreach and community volunteers was used to increase both provider and public awareness and this has been successful in destigmatizing death and raising awareness of the value of, and demand for, palliative care nationally (18). In comparison, the literature suggests that there is not the same demand for services amongst older populations and that this reticence to engage with health systems is resulting in late-stage presentation, poorer care outcomes and limited participation in clinical trials. Increasing awareness of the unmet needs for geriatric oncology, both amongst potential patients and decision makers, will be critical to build support for investing in the physical and human resources needed to develop or scale-up services.

Responding to outstanding challenges in geriatric oncology

While there are several valuable parallels between geriatric oncology and palliative care, the former is faced with some unique challenges to the scale-up of services. All policy and programme responses must be grounded in a robust evidence base, but for geriatric oncology there is a global shortfall in data and research. The regular inclusion of upper age restrictions for participation in research studies and clinical trials limits the applicability of study conclusions to older populations. Moreover, many countries' national statistics do not encompass older age groups and the data that much of the global reporting depends on either do not disaggregate by age or set age caps (19). A 2018 review of national cancer control plans (NCCPs), explored a number of key metrics indicating the comprehensiveness of the planning, including the needs of vulnerable groups. However, the review did not include indicators relating to older people with cancer. Few NCCPs include attention to older populations and this is perhaps symptomatic of the limited recognition of their needs. As the foundation for national action on cancer, NCCPs represent a logical starting point for comprehensive national advocacy around geriatric cancer.

Moreover, when assessing the impact of cancer on older populations, it is vital to consider the affordability of care. As countries look to implement financial protection measures as part of the drive to universal health coverage (UHC), older people are a key vulnerable group. Affordability of care is a large barrier for older patients with cancer, particularly

those individuals who may already be disadvantaged due to socioeconomic group, ethnicity or educational attainment. The long-term nature of many geriatric treatment pathways and the increasing use of novel treatments, particularly in high-income countries, pose an increasing financial burden for older people with limited financial flexibility. For example, in Nigeria, only 3% of the population is enrolled in the National Health Insurance Scheme, causing older patients with cancer to rely heavily on family and community support to fund their care (21). In the United States, Medicare beneficiaries, who are largely on fixed incomes, have a mean annual out of pocket spending of US\$ 8,115. Financial protection measures, such as national and non-governmental organization subsidies and reducing cost sharing, will be important to limit the financial burden of cancer care on older populations and are part of increasing health equity.

As discussions around the expansion of geriatric oncology develop further, it is important to recognize the political agency of older people in policy discussions, and the importance of engaging them in conversations at national and global levels about disparities in access to essential services. To date, these voices have been missing from the debate. In many countries, older people are an influential election demographic with the power to help drive significant reforms nationally. In Canada, 82% of people between the ages of 65 to 74 voted in the 2011 federal election, compared to 50% between the ages of 18 and 24 (22). If harnessed, this growing population could become influential advocates for increased investment in health systems, and a stronger focus on the health needs of older people.

When thinking through how we are approaching cancer and a globally ageing population it is helpful to draw on other disease programmes, including those of communicable diseases that have a strong equity focus, are patient-centred and participatory. From the authors' perspective, the approaches used by the palliative care movement promote a holistic view of patient management and have the potential to help shape and inform cancer control programmes within the framework of a life course approach. This should not lead people to assume we can directly transpose the palliative care model, nor that geriatric cancer patients should only be

offered palliative care. Instead we see this as a contribution to the necessary conversation about how we respond to the needs of the majority of cancer patients globally. As UICC, we welcome the opportunity to discuss the further scale-up of services and how different approaches can promote health equity and address the needs of older populations effectively as part of a commitment to UHC and its rallying cry to "leave no one behind". ■

Acknowledgements

With kind thanks to the Kirstie Graham, Mélanie Samson, Zuzanna Tittenbrun and the International Society for Geriatric Oncology for their review.

Rowena Tasker, BA, MA, is the Global Advocacy Manager in the Knowledge, Advocacy and Policy Team at the Union for International Cancer Control (UICC) where she focuses on global health discussions, particularly follow-up to the UN High-level Meeting on UHC. Rowena holds a Master's in Global Health and Development from University College London and a Bachelors in Geography from the University of Oxford.

Philip Martinez works in the Knowledge, Advocacy and Policy Team of the Union for International Cancer Control (UICC). Prior to joining UICC, he worked as a lab manager in a memory and neuroscience lab at Cornell University and clinical research assistant with the Translational Research Institute on Pain in Later Life at Weill Cornell Medical College. He is a rising fourth year student at Cornell University pursuing a BS in biological sciences with a concentration in neurobiology and behaviour. In addition to this, he is pursuing minors in gerontology and business.

Dr Sonali Johnson is Head of Knowledge, Advocacy and Policy at the Union for International Cancer Control (UICC). Her main area of work is to ensure that cancer prevention, treatment and care are positioned within the global health and development agenda. She holds a PhD and post-doctorate diploma in public health and policy from the London School of Hygiene and Tropical Medicine and an MSc in Gender and Development from the London School of Economics and Political Science.

References

1. United Nations, Department of Economic and Social Affairs, Population Division (2019) World Population Ageing 2019, Highlights. <https://www.un.org/en/development/desa/population/publications/pdf/ageing/WorldPopulationAgeing2019-Highlights.pdf> (accessed 25 March 2020)
2. International Agency for Research on Cancer (2018) GLOBOCAN 2018, Estimated number of new cancer cases 2018, all cancers, both sexes, ages 65+ http://gco.iarc.fr/today/online-analysis-pie?v=2018&mode=cancer&modepopulation=income&population=900&populations=900&key=total&sex=0&cancer=39&type=0&statistic=5&prevalence=0&population_group=0&ages_group%5B%5D=13&ages_group%5B%5D=17&nb_items=7&group_cancer=1&include_nmsc=1&include_nmsc_other=1&half_pie=0&donut=0&population_group_globocan_id= (accessed 25 March 2020)
3. Soto-Perez-de-Celis E et al. (2017) Global geriatric oncology: Achievements and challenges. *Journal of Geriatric Oncology*, 8: 374-386
4. Extermann, M et al. (2020) Top priorities for the global advancement of cancer care in older adults: An update of the International Society of Geriatric Oncology (SIOG) 10 Priorities Initiative. *Lancet Oncology* (in press)
5. Extermann M (2010) Geriatric Oncology: An Overview of Progresses and Challenges. *Cancer Research and Treatment*, 42(2): 61-68
- 6 World Health Organization (2017) "Best buys" and other recommended interventions for the prevention and control of noncommunicable diseases. <https://apps.who.int/iris/bitstream/handle/10665/259232/WHO-NMH-NVI-17.9-eng.pdf?sequence=1> (accessed 6 April 2020)
7. World Health Organization (2014) Strengthening of palliative care as a component of comprehensive care throughout the life course (resolution WHA67.19) <https://apps.who.int/medicinedocs/documents/s21454en/s21454en.pdf> (accessed 6 April 2020)
8. World Health Organization (2020) WHO Definition of Palliative Care. <https://www.who.int/cancer/palliative/definition/en/> (accessed 25 March 2020)
9. Lundqvist M et al (2018). Cost-effectiveness of comprehensive geriatric assessment at an ambulatory geriatric unit based on the AGE-FIT trial. *BMC Geriatrics*, 18(1), 32.
10. Åhlund K et al (2017). Effects of comprehensive geriatric assessment on physical fitness in an acute medical setting for frail elderly patients. *Clinical interventions in aging*, 12, 1929–1939.
11. Terret C (2005) Geriatric Oncology - a challenge for the future. *European Oncology Review*, 24-6
12. International Society for Geriatric Oncology (2020) Comprehensive Geriatric Assessment (CGA) of the older patient with cancer. <https://www.siog.org/content/comprehensive-geriatric-assessment-cga> (accessed 3 April 2020)
13. Fainsinger RL, Brenneis C, Fassbender K (2007) Edmonton, Canada: A Regional Model of Palliative Care Development. *Journal of Pain and Symptom Management*, 33(5): 634-639.
14. Rajagopa MR et al. (2014) Creation of Minimum Standard Tool for Palliative Care in India and Self-evaluation of Palliative Care Programs Using It. *Indian Journal of Palliative Care*, 20(3): 201-207
15. Sifer-Rivière L et al. (2011) What the specific tools of geriatrics and oncology can tell us about the role and status of geriatricians in a pilot geriatric oncology program. *Annals of Oncology*, 22(10): 2325-2329
16. Shah BK, Shah T. (2017) Home hospice care in Nepal: a low-cost service in a low-income country through collaboration between non-profit organisations. *The Lancet Global Health*, 5(1): S19.
17. Hsu T et al. (2020) Identifying Geriatric Oncology Competencies for Medical Oncology Trainees: A Modified Delphi Consensus Study. *The Oncologist* (in press).
18. Fraser B et al (2017). Palliative Care Development in Africa: Lessons from Uganda and Kenya. *Journal of Global Oncology*, 2018;4, 1-10.
19. HelpAge International & AARP (2019) Global AgeWatch Insights 2018: Report, summary and country profiles
20. Romero Y et al. (2018). National cancer control plans: a global analysis. *Lancet Oncology*, 19(10): e546-e555
21. Kiri VA, Ojule AC (2020). Electronic medical record systems: A pathway to sustainable public health insurance schemes in sub-Saharan Africa. *Nigerian Postgraduate Medical Journal*, 27(1): 1-7
22. Uppal S, LaRochelle-Côté S (2012). Factors associated with voting. *Perspectives on Labor and Income*, 24: 1-15

My Child Matters: An initiative of the Sanofi Espoir Foundation



Valentine Leuenberger, Laurence Bollack, Valérie Faillat and François Desbrandes, Sanofi Espoir Foundation; and **Julia Challinor**, International Society of Paediatric Oncology (SIOP)

Although therapeutic progress is constantly creating new hope, there are still endemic health inequalities. The disparity evident between the North and South is also reflected in the widening inequity inside wealthier countries.

Urgency inevitably focuses on the poor. But to make an effective impact, we must improve on a stepwise approach. We need to go beyond just the symptoms and focus on the causes if we want to truly address social and personal vulnerability. This means identifying the roots of the fragile, endangered life journeys of the vulnerable individuals and families that we encounter. Anticipating and understanding the factors that impact on effective interventions is necessary, so we can act with direct benefit.

To reverse the inequality curve, we advocate for a comprehensive approach to each individual. This includes treating, educating, housing, informing, protecting and reintegrating those in need. We are working to provide comprehensive and inclusive support, which is the only guarantee of a newfound autonomy that can put these families back on the path towards hope. Based on conviction and pragmatism, this approach is now being widely shared, and we are stimulating the creation of an entire ecology of civil society actors from private, institutional, political and other systems who are used to working sector by sector. We also continue to deal with difficult and sometimes neglected issues, such as childhood cancer in poor countries or support for migrants. As always, everywhere we look we seek out effective and lasting collective remedies.

In line with international and national initiatives that combine multiple approaches and foster more integrated innovation, we are expanding the boundaries of our action to maximize impact. These new dynamics are creating an innovative form of more responsible and forward-looking sponsorship that is

stimulating collaboration and solidarity. Once again, there is greater strength in unity.

The Sanofi Espoir Foundation was created in October 2010 by Sanofi to consolidate more than 20 years of commitment to national and international solidarity

The Sanofi Espoir Foundation's mission is to contribute to reducing health inequalities among populations that need it most by applying a socially-responsible approach. Its commitment is focused on three key targets:

- ➔ Supporting mothers and unborn children in low- and middle-income countries (LMICs); 2.5 million children die each year during their first month of life (World Health Organization, 2020), to which another 2.6 million stillbirths must be added, mostly in these settings (World Health Organization, 2020a).
- ➔ Supporting children with cancer in LMICs; only 20% of children with cancer in certain LMICs will recover, against 80% in most high-income countries (Ward et al., 2019). Cancer is a leading cause of death among children worldwide (World Health Organization, 2020b).
- ➔ Accompanying the life journeys of the most vulnerable communities in France; poverty is not declining in France and the country is still creating highly challenging conditions for young people. (Institut National de la Statistique et de Études Économiques, 2020)

The Foundation naturally responds to humanitarian emergencies, but focuses primarily on long-term partnerships

to act on recurrent issues such as healthcare professional education and clinical training, disease prevention and access to care.

Supporting children with cancer in low- and middle-income countries

Giving every child an equal chance of survival

Cancer is one of the major causes of death in children. While the survival rate for many childhood cancers is 80% in resource-rich countries, this can fall to less than 20% in some resource-limited countries. The main reasons are poor access to diagnosis and appropriate treatment, scant numbers of trained healthcare personnel and high rates of treatment abandonment, often due to financial constraints.

A collective approach throughout the health journey

Care provision involves the key steps of access to information, diagnosis, treatment and supportive care. From 2005, through our My Child Matters programme, our awardees have tackled all of these issues to improve the chances of a cure. We are particularly proud to have helped provide the first stem cell transplant for a four-year-old girl in Paraguay.

In paediatric oncology, care is based on a multidisciplinary response backed by networking. Appropriate care is a health journey that must take account of the specific conditions in each country.

We are supporting projects around 'Six Themes' all recognized as key to sustainably improving the conditions of children and adolescents living with cancer:

- ➔ cancer registries;
- ➔ professional education and training/capacity-building;
- ➔ early detection;
- ➔ supportive care and pain control;
- ➔ access to care;
- ➔ addressing treatment abandonment.

To date, together with our partners we are proud of the significant results we have achieved – 30,000+ child/

adolescent beneficiaries and 90,000+ healthcare professionals trained. In several countries the impact of this initiative has been highlighted in prestigious journals such as *The Lancet Oncology* (Howard et al., 2018).

What's new? What's next?

The challenges of childhood cancer care in LMICs remain significant.

The vast majority (90%) of the world's children live in LMICs and the inequalities are huge compared to those in high-income countries. In low- and lower-middle-income countries, "children with cancer are about four times more likely to die

Engaging

Working as closely as possible with conditions on the ground, we deliver immediate health solutions and direct access to care. To best respond to local situations, we rely on joint actions and co-construction rather than on purely solo efforts.

Energizing

Guided by a global approach to life journeys, our action is fundamentally collective and holistic. This is why we focus closely on engaging with and uniting actors right across the medical and social spectrum to help them interact and drive change. We position ourselves as a catalyst of solidarity acting to reduce vulnerabilities.

4 action tracks

Reinforcing

Quality care from the appropriate actors and the tools that are essential for reducing health inequalities. Training, information and awareness-raising for all stakeholders are crucial in reinforcing our actions over the long term.

Innovating

In synergy with our founder Sanofi, innovation is a key driver. Innovation can be technical (telemedicine, telepathology, etc.) or practical – redesigning our work and acting jointly with partners through our comprehensive approach. We aim to accelerate all forms of innovation and make them accessible to as many end users as possible in the general interest.

Figure 1: Map showing the geographical location of Sanofi Espoir projects



of the disease than children in high-income countries” (WHO 2020b).

As Dr Tedros, WHO Director-General, said, “...survival rates in poor countries are scandalously lower than those in wealthy countries” (WHO 2020b). To tackle these inequalities, in 2018, WHO launched the Global Initiative for Childhood Cancer (WHO 2020b). Our Foundation is strongly committed to this goal and is increasingly focused on low- and lower-middle-income countries. Through our LMIC strategy, we are committed to strengthening our programme in Africa and South East Asia where the vast majority of health inequalities are located. We act with our partners on all levels to efficiently and sustainably improve life conditions and the survival rate of children and adolescents with cancer.

We are currently supporting 34 active projects; 10 new projects were funded in 2020 in low- and lower-middle-income countries, which now represent two-thirds of our total budget allocation. With 14 projects in Africa and 8 projects in Asia, we are focusing on the most vulnerable regions and supporting our partners with their roadmaps, especially in pilot countries engaged in the WHO Global Initiative for Childhood Cancer (e.g., Myanmar, Peru, Ghana and Morocco).

We are working with our partners to strengthen regional networks and reference centres.

The following examples illustrate this specific approach:

1. Two pathology reference centres in sub-Saharan Africa

The development of two reference centres for pathology is based on a twinning approach between Accra and Dakar, with a roadmap phased over the next 4-5 years. The two cities will act as hubs for the West Africa sub-region, covering both French- and English-speaking countries, and will benefit from equipment, support and expertise by:

- ➔ sharing state-of-the-art techniques;
- ➔ developing a network using common tools like i-PATH;
- ➔ sharing experiences and expertise with second-opinion diagnosis;
- ➔ training pathologists.

Both objectives aim to ensure:

- ➔ the permanent availability of appropriate and well-maintained equipment, practice and knowledge throughout the region;
- ➔ an economic rationale for efficiency and sustainability.

The projects are structured under a strong country ownership model that we believe is key to ensuring appropriate buy-in and long-term viability. The two projects are locally driven. The Dakar project is run as a federation of three major

hospitals and the University of Cheikh Anta Diop (UCAD), and the Accra project is the responsibility of the University of Ghana’s Medical School’s Pathology Department.

In addition to My Child Matters, both projects are strongly supported by highly-committed international partners, such as the Alliance Mondiale Contre le Cancer (AMCC) for Dakar and St Jude Children’s Research Hospital for Accra.

2. African School of Paediatric Oncology

Sustainable development cannot be achieved without a strong capacity-building programme for healthcare professionals. Of course, this is a long-term approach. In 2012, the French African Paediatric Oncology Group (GFAOP) established the African School of Paediatric Oncology (EAOP), with two universities and permanent support from My Child Matters.

This is a comprehensive training and certification programme in paediatric oncology for French-speaking African countries. To date, impressive results have been published (Hessissen et al, 2019), with a rapid increase in the pool of qualified paediatric oncology professionals in the region.

In 2020, a new set of training modules on pathology and diagnosis on an e-learning platform, in connection with the Reference Centre project in Dakar, is being developed with My Child Matters’ support. This new tool is designed to reach both pathologists and physicians in order to develop a common language of fundamentals to ease, improve and finally speed up communication during the diagnosis process.

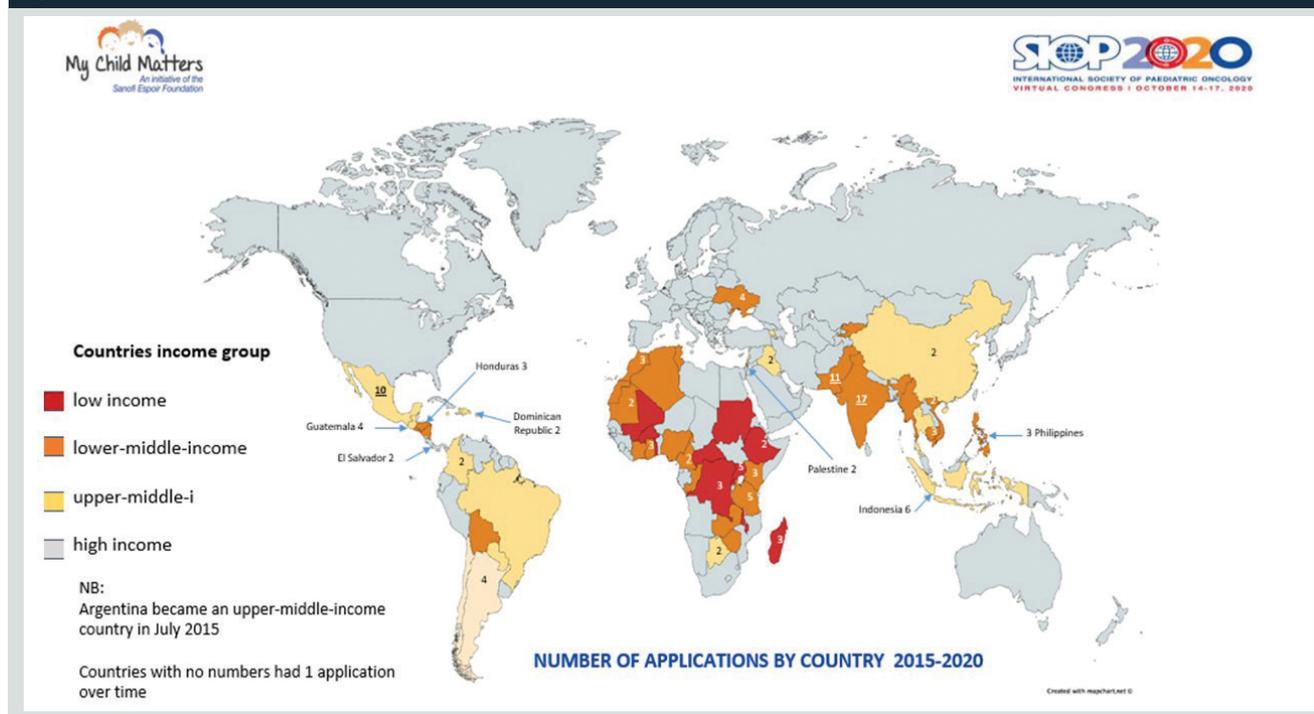
3. The My Child Matters Nursing Awards

Building on the successful My Child Matters funding programme for children and adolescents with cancer in LMICs launched in 2006, at the 2015 International Society of Paediatric Oncology (SIOP) Congress in Toronto, the Sanofi Espoir Foundation announced a new initiative: My Child Matters funding for nurses in these settings in collaboration with SIOP.

In 2015 and 2016, My Child Matters nursing grants of €5,000 for 10 projects were awarded. In 2018–2019, this was modified to a €10,000 biennial grant for five projects, since it was noted that one year was too short to complete most projects, so we adjusted the grant to give €10,000 to just five awardees for a 2-year project instead.

Grant applications are advertised on the SEF and SIOP websites and social media. Applicants are requested to develop and highlight innovative approaches to nursing service and practice that improve the care and quality-of-life of children and adolescents with cancer by focusing on education, professional practice or research. Expert paediatric oncology nurses review and score applications accepted in English and

Figure 2: The number of applications by country 2015–2020



French. Initially, applications were accepted from all LMICs, however, since 2018, eligibility has been restricted to lower-middle and low-income countries due to the demand.

In 2015, 36 eligible applications were received and 27% were awarded a grant. A total of 60% of funded projects were in lower-middle or low-income countries. In 2016, 26 eligible applications were received and 37% were awarded a grant. Again, 60% were in lower-middle or low-income countries. The 2018–2019 call for new projects produced 61 eligible applications from 33 countries. Despite the good quality of the projects, only 8% (five nurses) were awarded a grant. In total, 90% of projects that have been supported from 2015–2019 were successfully implemented. Incomplete grants had significant local nursing personnel or national political issues.

Two changes were made for the 2020 call for nursing projects to increase our impact on childhood cancer in regions that need it most. The Foundation continued its focus on low- and lower-middle-income countries only and doubled its support to €100,000 in total to be shared among awardees in honor of the WHO International Council of Nursing, Year of the Nurse. A total of 26 eligible applications were received, and 12 projects were funded, all in low- and lower-middle-income countries (three awardees received a share of one €10,000 grant).

Examples of My Child Matters nursing grants include projects to address the infection control education of nurses at the Indus Hospital in Karachi, Pakistan; a paediatric oncology nursing orientation programme in Jakarta, Indonesia; early cancer detection using an ambassador and mobile money

transfer in northwest Cameroon; and a childhood cancer awareness programme across Vietnam. In many cases, the nursing projects included collaboration with local and national nursing organizations, schools of nursing, non-governmental organizations and other critical stakeholders.

The Sanofi Espoir Foundation have awarded 37 nursing grants since the creation of the My Child Matters nursing awards in 2015 and sponsored 16 nurses over the last four SIOp congresses for project presentations. We believe that in-person presentations at SIOp serve to inspire other nurses and demonstrate best practices in a variety of resource-limited settings.

As one of the few supporters of paediatric oncology nursing care in LMICs, the Sanofi Espoir Foundation, in partnership with SIOp, has shown leadership in the improvement of nursing care for the 90% of children and adolescents with cancer who live in resource-poor areas around the world. The nurses who have received funding have highlighted the wide range of nursing practice areas for improvement and demonstrated that positive change is possible in the quality of life of patients and their families they attend. One nurse awardee from Tanzania notes:

“There has been a lot of success that has been observed throughout the process. One was to be able to bring together regional and district medical officers and nursing officers, TANNA (Tanzania National Nurses Association) regional branch leaders and hospital management teams around the same table to discuss the situation of childhood and adolescent cancer in our country, particularly in the Southern Highland Zone. This action provided a

strong gateway for the implementation of the proposed activities. There was positive collaboration between the stakeholders and the project team. A sense of ownership of the project was developed with the stakeholders, as was observed in the mid-evaluation whereby every hospital visited had a supportive environment for the project. Nurses work in different hospital departments where they contribute to more than 60% of the health work force and had a great opportunity to interact with the community, especially in providing health education and in creating awareness of childhood and adolescent cancer.” Elianeth Anande Kiteni – Tanzania - MCM Nurse awardee 2018 (in her final report).

An oral presentation was given at SIOP 2020 entitled, “History and outcomes of the paediatric oncology nursing awards from the My Child Matters programme, an initiative of the Sanofi Espoir Foundation 2015–2020”. Moreover, a recent qualitative evaluation study, led by SIOP and the Sanofi Espoir

Foundation explored the experiences and the perceived impact of four selected My Child Matters nursing award projects in El Salvador, Central African Republic, Indonesia and Tanzania. Interviews were conducted with multiple stakeholders and the results will be published in a report and submitted to international scientific journals.

We will launch the sixth call for projects for the My Child Matters Nurses Awards in December 2021 and are looking forward to the applications, especially from nurses in low- or lower-middle-income or a French-speaking African country. If you are interested in submitting your project, watch our website for guidelines and deadlines: <https://www.fondation-sanofi-espoir.com> ■

Sanofi Espoir Foundation – 114 Rue La Boetie, 75008 PARIS, France

References

Hessissen L et al. “African School of Pediatric Oncology Initiative: Implementation of a Pediatric Oncology Diploma Program to Address Critical Workforce Shortages in French-Speaking Africa.” *Journal of global oncology* 5 (2019): 1-12.

Howard SC et al. “The My Child Matters programme: effect of public-private partnerships on paediatric cancer care in low-income and middle-income countries.” *The Lancet Oncology* 19.5 (2018): e252-e266.

Institut National de la Statistique et de Études Économiques (2020). Half of the people arrived in France in 2017 were born in Europe. Jérôme Lé INSEE FOCUS No 145 published 20/02/2019. <https://www.insee.fr/en/statistiques/4214556> Accessed November 9, 2020

Ward ZJ, Yeh JM, Bhakta N, Frazier AL, Girardi F, Atun R. Global childhood cancer survival estimates and priority-setting: a simulation-based analysis. *The Lancet Oncology*. 2019 Jul 1;20(7):972-83.

World Health Organization (2020). Newborn health. https://www.who.int/health-topics/newborn-health/#tab=tab_1 Accessed, 9 November 2020.

World Health Organization (2020a). Maternal, newborn, child and adolescent health.

The case for collective Commonwealth action on cervical cancer

Professor Isaac F Adewole (left), Gynaecologic Oncology Unit, Department of Obstetrics and Gynaecology, College of Medicine, University of Ibadan, Nigeria and **Dr Ophira Ginsburg** (right), Section for Global Health, Division of Health and Behavior, Department of Population Health, NYU Grossman School of Medicine, USA



Cervical cancer remains a public health challenge, particularly in the low-income and middle-income countries (LMICs) of the Commonwealth due to inequity, injustice and ignorance. The stark reality is that the global call by the World Health Organization (WHO) for the elimination of cervical cancer is only feasible in a few Commonwealth member countries. However, robust collective action that is driven by the highest political leadership could create a pathway for countries with a high burden of cervical cancer and weak health infrastructure to meet the 2030 targets of the cervical cancer elimination agenda. Thus, there is the need for genuine partnerships in research, and policies that will fit the local needs of individual countries. Indeed, single dose HPV vaccination with a “screen and treat” approach for those with premalignant cervical diseases may be a good alternative strategy to the conventional protocol in most Commonwealth countries. It is important that member countries should support each other to generate local evidence, health workforce development, infrastructure and healthcare financing for cervical cancer prevention and treatment. This will ensure that no one is left behind. The time for action is now.

Cervical cancer as a public health concern

Cervical cancer, the second most common cancer among women after breast cancer globally, has been described as a disease that manifests inequity, injustice, and ignorance (1). Whilst most high-income countries, particularly in the West, had initiated the process of eliminating cervical cancer, the majority of low- and middle-income countries in the Commonwealth are experiencing an increasing or static incidence and mortality of cervical cancer (2). Most of these high-burdened countries are members of the Commonwealth (3). Worldwide, it was estimated that every two minutes a woman dies from cervical cancer. Of the half a million cases of newly diagnosed cervical cancer and more than a quarter of a million women who die from cervical cancer annually, over 70% are in the low- and middle-income countries (4, 5). Commonwealth countries account for 40% of the global cervical cancer incidence and 43% of cervical cancer mortality. Women in Commonwealth countries with a high HIV burden – South Africa, Tanzania and Zambia – are at increased risk of morbidity and mortality from cervical cancer. Estimates suggest that the burden of new cases and mortality from cervical cancer might increase by 55% and 60%, respectively, in the Commonwealth member countries if there is no appropriate investment (2, 5).

Effective cervical cancer strategy prevention and control is available

Generally, persistence of high-risk human papillomavirus (HPV) infection is a necessary cause of cervical cancer, accounting for 99% of all cases (5). Although there might be variation in the pattern of detectable HPV genotypes in the invasive cervical cancer samples, HPV 16 and 18 have been reported in more than 70% (6, 7). Thankfully, there are efficient and cost-effective vaccines – Cervarix, Gardasil and Gardasil 9 – that can be deployed and administered to young girls before sexual debut at the population level to prevent HPV infection acquisition and persistence (8). Catch-up HPV vaccination for sexually active women has also been shown to be useful. Many high-income countries have adopted a gender neutral policy of vaccinating girls and boys, as a strategy to quickly promote community herd immunity against HPV (9).

A recent review by the World Health Organization (WHO) showed that only two countries in Africa (Rwanda and Seychelles) have achieved 80% national HPV vaccine coverage, while many other countries have not introduced the vaccine (9–11). In addition to mass vaccination, screening for premalignant lesions and prompt treatment of early invasive cancer are effective secondary and tertiary preventive strategies for cervical cancer, respectively (11). In an attempt

to ensure that cervical prevention and control is accessible to all women, WHO prescribed a modified algorithm for cervical cancer (1). Again, a number of countries in the Commonwealth, particularly in Africa, do not have national policies and or implementation plans for screening services (1).

The landscape of cervical cancer in the Commonwealth

The increasing burden of cervical cancer in Commonwealth member countries does not appear to be due to a new histological type or increased aggressiveness of a variant HPV subtype; it is largely as a result of the high prevalence of risky sexual behaviour, poor knowledge and health-seeking behaviours of women, lack of capacity to effectively implement national screening services and prompt diagnosis and treatment of early stage cervical cancer (1, 12). For example, hospital-based studies have shown that most women present in advanced stage (i.e., Figo Stage 2b and above) when a cure is no longer envisaged and the five-year survival is low (1).

In Nigeria, more than 7 out of 10 women that present with cervical cancer for the first time at the gynaecological clinic already have Stage III of the disease (13, 14). In this scenario, a cervical cancer patient is usually described as a woman with postcoital or abnormal vaginal bleeding, foul smelling vaginal discharge, and weight loss with or without urinary

or feecal incontinence. This scenario, often the end stage of the disease spectrum, reflects the lack of awareness and understanding about the disease, prevention and treatment and failure of the health system (12-14). In contrast, in some member states where effective national screening programmes have been operational for decades, advanced invasive cervical cancer is rare and women with invasive cervical cancer are usually detected early, offered surgery and radiotherapy, with excellent clinical outcomes such as high five-year survival rates (2).

In low- and middle-income countries, the challenges of access to high-quality affordable healthcare are myriad (1). Healthcare financing in many countries in Africa is also fraught

with no insurance coverage for basic healthcare and cancer care (1). High out-of-pocket costs make access to cervical care very challenging since most treatment protocols include radiotherapy and chemotherapy, which are very expensive. The poor investment in health infrastructure generally also has a negative toll on cervical cancer control. There are a number of countries in the Commonwealth that have inadequate health infrastructure including basic equipment for cervical cancer screening and treatment of pre-cancers. Availability of radiotherapy machines is one the key infrastructural challenges in Commonwealth countries. According to the 2019 IAEA report, many countries in Africa have less than 5

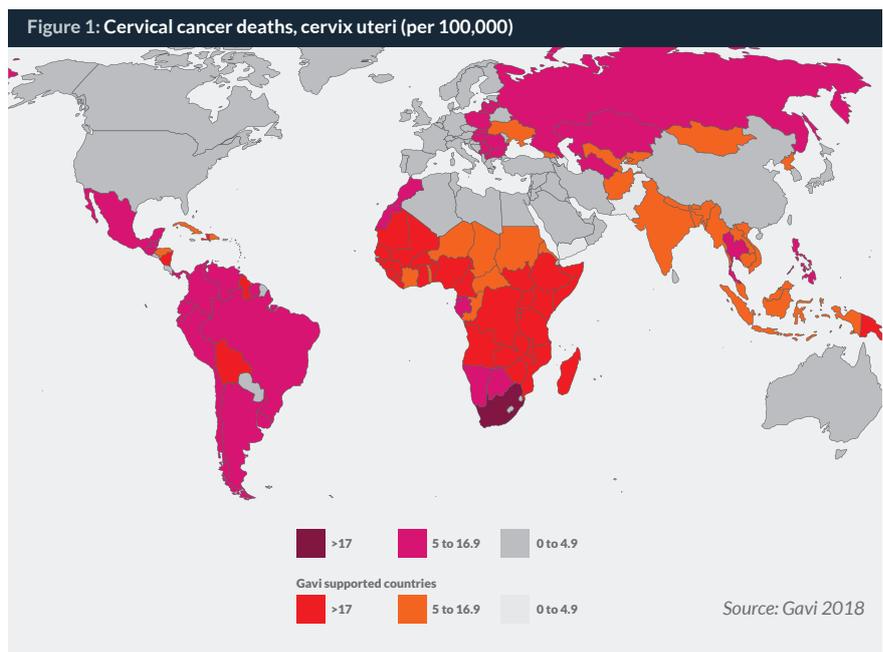
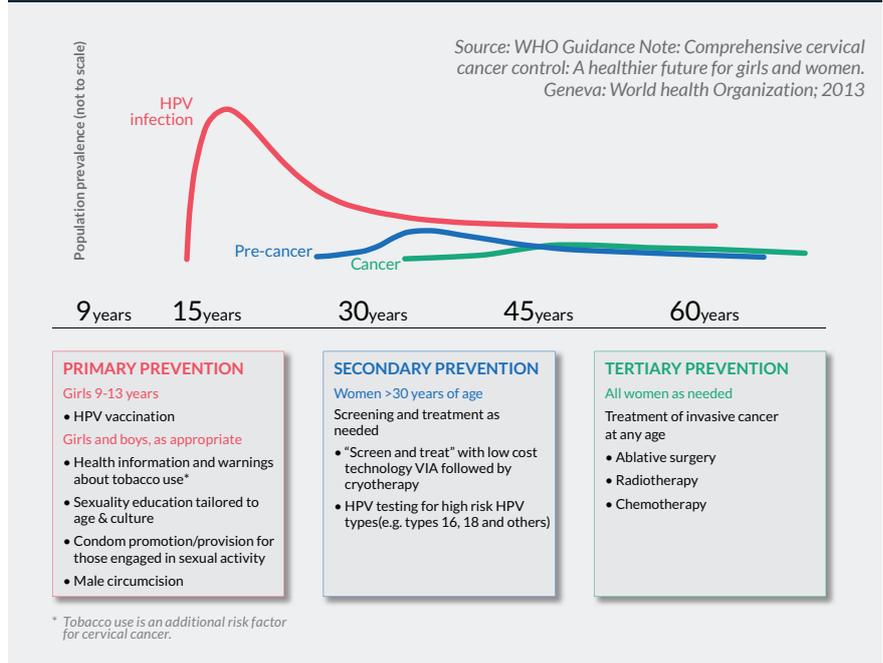
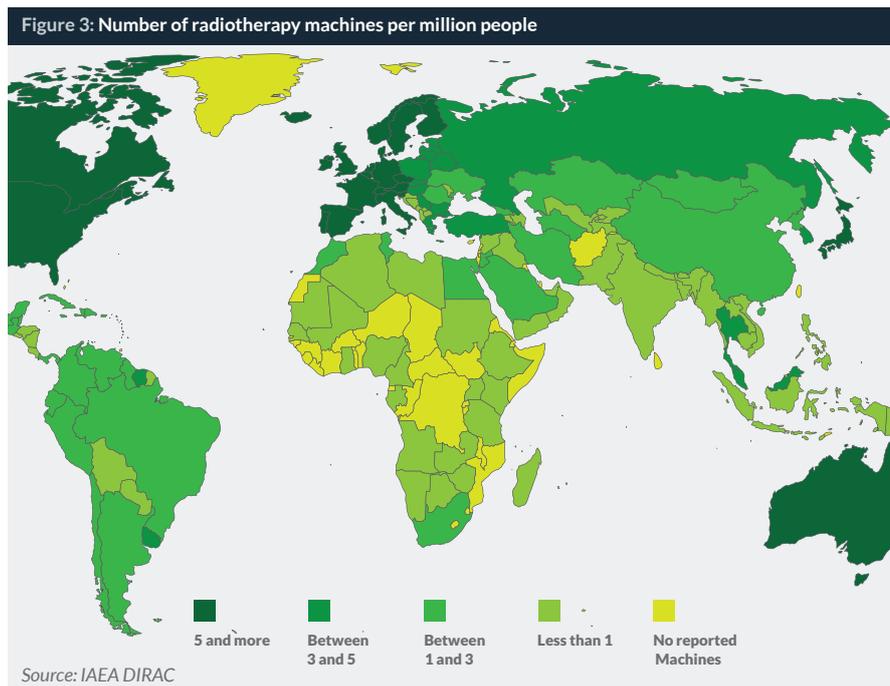


Figure 2: Overview of programmatic interventions over the life course to prevent hpv infection and cervical cancer





radiotherapy machines (15, 16). Nigeria, with a population of 200 million, has fewer than 10 functional radiotherapy machines, considerably less than the required 1 machine per million people (15-17). The inadequate supply of radiotherapy machines has negatively impacted on the survival of cervical cancer patients. However, Australia and the United Kingdom have more than 5 functional radiotherapy machines per million people and treatment at these centres is covered by health insurance (15, 16).

The trio of ignorance, poverty and disease is responsible for the high burden of diseases in Africa. Poor awareness about the aetiology of cervical cancer, especially among women and young girls, has been reported to be associated with poor health-seeking behaviour (2). Women with poor knowledge of cervical cancer tend to present late when they eventually develop the disease.

Goal for action

The overarching goal for action for all member states in the Commonwealth is to ensure that “every person has access to cancer prevention and screening, those with cancer are diagnosed early, have timely referrals and access to access to the highest standard of specialty care, where competent health workers provide quality, affordable treatment in an efficient system that delivers maximum outcomes” (18). Following the global call for the elimination of cervical cancer by the Director General of WHO in 2018, every country in the Commonwealth must, as a matter of priority, initiate a national policy and programme that aligns with the elimination agenda (18). Given the disparity in resources and implementation efforts for the control of cervical cancer in the Commonwealth,

it is imperative that member states form a coalition for collective action in cervical cancer prevention and control. This would cover primary, secondary and tertiary prevention, including supportive and palliative care.

Rationale for collective action for cervical cancer prevention and control

1. Global elimination agenda: This is a global effort and few countries can do it alone: It is imperative that member nations in the Commonwealth position themselves to adopt, introduce and implement the global elimination agenda for cervical cancer control. The thrust of the agenda is to eliminate cervical cancer as a public health

problem when all countries reach an incidence rate of less than 4 cases per 100,000 women (18). The expectation is that every country would meet the global target by 2030 – 90% coverage of HPV vaccination of girls; 70% coverage of screening; and 90% management for women with pre-cancers and invasive cervical cancer (1, 18, 19)

- 2. Political commitment and action needed: A resolution is likely to be adopted at the 73rd World Health Assembly.** High-level political commitment among member countries in the Commonwealth is critical as this will guarantee prioritization, investment and aggressive programmatic implementation. Individual countries should ensure that their cervical control strategy is driven by the highest political leadership in order to facilitate the required action necessary for progress towards the elimination of cervical cancer. For example, the President of Rwanda played a critical role in generally reshaping the health system of his country, including HPV vaccination (20).
- 3. Differential capacity and infrastructure to control cervical cancer:** Vast disparities exist between member states in the Commonwealth in terms of human resources and health infrastructure, including well-equipped diagnostic and treatment facilities necessary for comprehensive services. Investment in the training of frontline health workers of cadres through acquisition of skills on screening and treatment of premalignant and early cervical cancer should be explored between member countries.

Commonwealth member states need to use evidence-based data for collective action

Establish a Commonwealth evidence base for cancer control

to support health professionals, policy makers and researchers involved in cancer control. Although the primary data to understand the social context and epidemiological risk factors of cervical cancer is available, data to understand possible differences in the response, as well as toxicities of different treatment protocols, are lacking in many Commonwealth countries. Basic science research on cervical cancer is not fully developed in Africa, and investment in this type of research will help in the development of new treatment protocols that may be beneficial to the survival of patients, policy formulation and future research. For example, it will be desirable for some countries in the Commonwealth, particularly in Africa, to initiate clinical trials for a single-dose HPV vaccination or single screening for premalignant lesions of the cervix among sexually active women (21). These cost saving strategies for primary and secondary prevention of cervical cancer would need to be further tested to consolidate the initial evidence from other countries.

Apart from generating national evidence, it is also desirable that member states share research findings including new drug or treatment protocols to promote evidence-based resource-tailored services for cervical cancer. Government, corporate organizations and foundations should make funds available for cutting edge research in different aspects of cervical cancer.

Conclusion

The Commonwealth consists of a highly varied group of member nations in terms of policies, implementation strategies and progress towards the elimination of cervical cancer. There are countries that are almost at the verge of eliminating cervical cancer, whereas there are others that are yet to initiate national policy and implementation strategies for the disease. Cervical cancer still remains a public health challenge in many Commonwealth countries, where most women present with advanced disease that is not amenable or feasible to treat with curative intent. Elimination of cervical cancer is possible, provided a genuine coalition is formed among

member countries to address the ambitious targets for HPV vaccination, screening and treatment. Adequate investment in evidence generation, healthcare workforce development and infrastructure, and the introduction of appropriate healthcare financing models under a political leadership that prioritizes cervical cancer control can eliminate this entirely preventable cancer. Urgent action is needed now. ■

Professor Isaac F Adewole is a gynaecologist at the College of Medicine, University of Ibadan, Nigeria. He is the immediate past Minister of Health of Nigeria, former Vice Chancellor, University of Ibadan, Nigeria, and former President of the Africa Organisation for Research and Training in Cancer (AORTIC). He has served on several national and international organizations' boards and programmes on research and policy for cervical cancer control. He has led research projects on prevention, diagnosis and capacity building on cervical cancer in Nigeria. He has more than 220 publications on HIV, human papillomavirus and cervical cancer. He is a sexual health advocate, particularly promoting safe sexual and reproductive health among adolescents and young adults. He is also a community man, offering professional service to underprivileged girls and women through his Isaac Folorunso Adewole Foundation (IFAF).

Dr Ophira Ginsburg is a medical oncologist and global women's health researcher with technical and policy expertise in noncommunicable diseases prevention and management. She is the Director of the High-Risk Cancer Genetics Program and Associate Professor in the Section for Global Health, Department of Population Health at New York University School of Medicine. Formerly based at the University of Toronto, from 2015 to 2016 she was a Medical Officer at WHO, and continues to serve as a consultant to several UN agencies, providing technical assistance to member states on national cancer control planning and policies. She is leading a new study funded by the US National Institutes of Health ("Cancer Moonshot" programme), to improve access to cancer genetics services via primary care clinics in New York.

References

1. Gossa W, Fetters, MD. How Should Cervical Cancer Prevention Be Improved in LMICs? *AMA J Ethics* 2020; 22(2): E126-34.
2. Vu M, Yu J, Awolude OA, Chuang L. Cervical cancer worldwide. *Curr Probl Cancer* 2018; 42(5): 457-65.
3. Beddoe AM. Elimination of cervical cancer: challenges for developing countries. *Ecancermedicalscience* 2019; 13: 975.
4. International Agency for Research on Cancer. World Health Organization. Cancer fact sheets: cervix uteri. <http://gco.iarc.fr/today/data/factsheets/cancers/23-Cervix-uteri-fact-sheet.pdf>. (Accessed 14/03/2020). 2018.
5. Arbyn M, Weiderpass E, Bruni L, et al. Estimates of incidence and mortality of cervical cancer in 2018: a worldwide analysis. *Lancet Glob Health* 2020; 8(2): e191-e203.
6. Denny LA, Sankaranarayanan R, De Vuyst H, et al. Recommendations for cervical cancer prevention in sub-saharan Africa. *Vaccine* 2013; 31 Suppl 5: F73-4.
7. Okolo C, Franceschi S, Adewole I, et al. Human papillomavirus infection in women with and without cervical cancer in Ibadan, Nigeria. *Infect Agent Cancer* 2010; 5(1): 24.
8. Arrossi S, Temin S, Garland S, et al. Primary Prevention of Cervical Cancer: American Society of Clinical Oncology Resource-Stratified Guideline. *J Glob Oncol* 2017; 3(5): 611-34.
9. Bruni L, Diaz M, Barrionuevo-Rosas L, et al. Global estimates of human papillomavirus vaccination coverage by region and income level: a pooled analysis. *Lancet Glob Health* 2016; 4(7): e453-63.
10. Gallagher KE, Howard N, Kabakama S, et al. Human papillomavirus (HPV) vaccine coverage achievements in low and middle-income countries 2007-2016. *Papillomavirus Res* 2017; 4: 72-8.
11. Simms KT, Steinberg J, Caruana M, et al. Impact of scaled up human papillomavirus vaccination and cervical screening and the potential for global elimination of cervical cancer in 181 countries, 2020-99: a modelling study. *Lancet Oncol* 2019; 20(3): 394-407.
12. Williams-Brennan L, Gastaldo D, Cole DC, Paszat L. Social determinants of health associated with cervical cancer screening among women living in developing countries: a scoping review. *Arch Gynecol Obstet* 2012; 286(6): 1487-505.
13. Anorlu RI, Orakwue CO, Oyeneyin L, Abudu OO. Late presentation of patients with cervical cancer to a tertiary hospital in Lagos: what is responsible? *Eur J Gynaecol Oncol* 2004; 25(6): 729-32.
14. Awolude OA, Oyerinde SO. Invasive Cervical Cancer in Ibadan: Socio-Sexual Characteristics, Clinical Stage at Presentation, Histopathologic Distributions and HIV Status. *Afr J Infect Dis* 2019; 13(1): 32-8.
15. Balogun O, Rodin D, Ngwa W, Grover S, Longo J. Challenges and Prospects for Providing Radiation Oncology Services in Africa. *Semin Radiat Oncol* 2017; 27(2): 184-8.
16. Abdel-Wahab M, Fidarova E, Polo A. Global Access to Radiotherapy in Low- and Middle-income Countries. *Clin Oncol (R Coll Radiol)* 2017; 29(2): 99-104.
17. Leng J, Ntekim AI, Ibraheem A, Anakwenze CP, Golden DW, Olopade OI. Infrastructural Challenges Lead to Delay of Curative Radiotherapy in Nigeria. *JCO Glob Oncol* 2020; 6: 269-76.
18. The Lancet. Eliminating cervical cancer. *The Lancet* 2020; 395(10221): 312.
19. WHO EB recommends the adoption of the strategy for elimination of cervical cancer. <https://www.who.int/news-room/detail/05-02-2020-who-eb-recommends-the-adoption-of-the-strategy-for-elimination-of-cervical-cancer>. Accessed March 16, 2020
20. Binagwaho A, Wagner, C.M., Gatera, M, Karema, C. Nutt, C., Ngabo, F. Achieving high coverage in Rwanda's national human papillomavirus vaccination programme. *Bulletin of the World Health Organization*, 2012; 90: 623-8.
21. Brotherton JM, Budd A, Rompotis C, et al. Is one dose of human papillomavirus vaccine as effective as three?: A national cohort analysis. *Papillomavirus Res* 2019; 8: 100177.

The shifting global burden of cancer: Cancer Research UK's engagement with low- and middle-income countries

Bekki Field (left), Programme Lead, International Cancer Prevention, Cancer Research UK and
Caroline Mitchell (right), Research Grants and Communications Officer, India-UK Cancer Research Initiative



This article sets out explain how one charity, Cancer Research UK (CRUK), based in United Kingdom has developed an effective contribution to global cancer challenges. Through a focus on tobacco control, cervical cancer and global scientific research, CRUK has been able to leverage its resources to make an impact on low- and middle-income countries and their cancer control response.

Global cancer incidence is rising rapidly. Eighteen million people were diagnosed with cancer in 2018 and this figure is predicted to be 29 million by 2040. There are numerous factors underpinning this statistic – some of which are to be celebrated. People are living longer than before: progress which is especially marked in low- and middle-income countries (LMICs) as communicable diseases are tackled and economic development takes root. But new wealth is linked to a rise in cancer risk factors including obesity and smoking. This burden is being increasingly borne by the low- and middle-income world, which is facing an increase in cancer cases of 81% over the next two decades, according to the latest World Health Organization (WHO) World Cancer Report.

The COVID-19 pandemic continues to be catastrophic, with well over one million deaths recorded worldwide, and little sign that it will be brought under control until an effective vaccine is found. The indirect health consequences of the pandemic will also be far-reaching: with healthcare systems temporarily diverted towards tackling the virus, in the case of cancer care this has meant vastly reduced access to services across the prevention, diagnosis and treatment pathway. In the UK alone it is estimated that there will be up to 35,000 excess deaths caused by cancer due to delays and cancellations of vital services. At the time of writing, the impact of COVID-19 in LMICs appears uneven and is an evolving picture, but it seems inevitable that in settings where resources and access to effective cancer care are already limited, the risks are significant.

As the world's largest independent cancer charity dedicated to saving lives through research, Cancer Research UK (CRUK) has a major role to play, now more than ever, in

improving cancer outcomes – both in the United Kingdom, and internationally. COVID-19 has exemplified the necessity of global collaboration in an increasingly interconnected world. CRUK has helped save millions of lives, including through its pioneering work in radiotherapy, screening and chemotherapy, as well as its role in developing eight of the world's top 10 cancer drugs and in establishing the link between tobacco and cancer. Through enhanced collaboration we can enable and invest in ground-breaking research, share knowledge and deliver impactful system change through influencing policy development. CRUK's response to the shifting global burden of cancer is anchored by three key priorities: global health, global science and global partnerships.

Global health

Tobacco control

Smoking remains the single biggest cause of cancer. Although there is a slow downward decline in smoking prevalence globally, 80% of the world's 1.1 billion smokers live in LMICs and this proportion is set to rise. New wealth, aggressive tobacco industry tactics and the continued cultural salience of non-combustible products such as smokeless tobacco in many parts of the world, are some of the factors that combine to provide fertile ground for future generations of smokers.

Since 2016, CRUK's International Tobacco Control Programme (ITCP) has sought to accelerate implementation of the WHO Framework Convention on Tobacco Control (FCTC) – the world's first global health treaty. The ITCP has focused primarily on increasing tobacco taxes and reducing the affordability of tobacco in LMICs. Evidence continues to demonstrate that taxation is the single most effective measure

in reducing smoking prevalence, which also raises additional revenue for governments (which can and should be earmarked for investment in health). But implementation of the FCTC is a mixed picture. In LMICs there is a dearth of funding and staffing for tobacco control programmes. High-income countries have provided only minimal development funding to address this gap, despite the consequences of inaction in terms of lives lost and economic development.

With a £5 million investment over five years, the ITCP has funded policy research grants in 28 LMICs, forging relationships with influential global stakeholders along the way. Not only has this research expanded the evidence base on the utility of increasing tobacco tax in terms of both health outcomes and national income, but it has also increased the profile and capacity of researchers working on tobacco control in LMICs. This model has sustainability and flexibility at its heart; local actors are best placed to work with decision makers to help deliver policy change that positively impacts cancer outcomes. In four years, the ITCP has established a meaningful footprint on global tobacco research, with funding achievements including:

- ➔ working with the Framework Convention Alliance (FCA) – a global civil society network of over 500 organizations working on tobacco control – to support Parties in developing a Medium-Term Strategic Framework for the Framework Convention on Tobacco Control (FCTC), adopted at the Eighth Session of the Conference of Parties (COP) in 2018. The strategy is an important tool which Parties to the Treaty and civil society can use to review implementation efforts, and to highlight the need for sustainable funding to support these efforts;
- ➔ funding the FCTC Tax Knowledge Hub at the University of Cape Town, which delivers workshops and capacity building on tobacco taxation to policy makers and civil society. Examples of recent Knowledge Hub achievements include supporting the Chadian government in simplifying their tobacco tax in January 2019 to avoid loopholes often exploited by the tobacco industry (with revenue earmarked for the Ministry of Health), and persuading the government of Pakistan to simplify its tobacco tax system to avoid loopholes that can be exploited by tobacco industry pricing;
- ➔ publishing a series in the *British Medical Journal* that looked at tobacco tax in seven LMICs across four WHO regions, which established that contrary to tobacco industry claims, increases in tobacco tax do not lead to a rise in the illicit trade in cigarettes. Vital work as the tobacco industry’s own data “estimates” are often taken into consideration by governments reviewing their tobacco taxation.

The centrepiece for the global tobacco control community in 2020 was the FCTC Conference of the Parties (COP), which was due to be held in the Netherlands in November. One of the many global meetings postponed due to the pandemic, this hiatus has demonstrated the sometimes over-reliance of civil society on leveraging international meetings to achieve their objectives. Nevertheless, the postponement of the COP provides an opportunity for the community to regroup and react to the “new normal” ahead of the delayed meeting in November 2021. In the current context, securing additional investment in tobacco control in LMICs – both domestically and by high-income countries – will be challenging. But the use of health taxes to provide much needed revenue could be an increasingly compelling option for governments.

CRUK’s grantees and funding partners:

- ➔ International Development Research Centre (Canada)
- ➔ University of Cape Town, Economics of Tobacco Control Project and WHO FCTC Knowledge Hub on Tobacco Taxation
- ➔ American Cancer Society
- ➔ KIVU International
- ➔ Framework Convention Alliance

Cervical cancer prevention

The approach of the ITCP has shown that building the capacity of local actors – supported as appropriate by international experts – ensures relevant and sustainable solutions are developed to tackle complex health challenges head-on. Building on the ITCP’s success, CRUK recently expanded the remit of its international prevention work in order to support global efforts on cervical cancer prevention – responding to the WHO Director-General’s call for action towards the elimination of cervical cancer. A call particularly pressing for LMICs, where around 84% of cervical cancer cases occur.

CRUK has well-established interest and expertise on cervical cancer: helping prove the link between the human papillomavirus (HPV) and cervical cancer in the 1990s, which paved the way for the development of the HPV vaccine that now offers protection from the most common cancer-causing strains. The charity is co-funding – with the Bill & Melinda Gates Foundation and the National Cancer Institute (a part of the National Institutes of Health) – the PRIMAVERA trial in Costa Rica, which is testing the protective immunity of a single dose of the HPV vaccine.

CRUK’s new cervical cancer prevention programme will support implementation of the WHO Global Strategy towards

the Elimination of Cervical Cancer adopted in July – which for the first time globally brings together targets under three pillars: HPV vaccination, screening and treatment of pre-cancerous lesions, and treatment and palliative care. CRUK's vision is to invest specifically in the proposed 2030 target for 90% of girls to be fully vaccinated against HPV by 15 years of age. As co-chair of Cervical Cancer Action for Elimination (CCAIE), CRUK is helping coordinate a network of civil society actors advocating and collaborating on cervical cancer elimination, with the aim of becoming truly global in scope. CCAIE will support incremental realization of the Global Strategy's 2030 targets through advocacy at all levels: to drive country implementation, and to hold governments to account on this agenda.

The scale of the task can hardly be overstated, but if the international community coalesces in support of the Strategy, the figures for averted cervical cancer deaths could be approximately 2 million by 2040, 4.5 million by 2050, 39 million by 2100, and 62 million by 2120.

Global science and global partnerships

CRUK seeks to bring together the best scientific minds to address global challenges in cancer. India has long been recognized as a priority in terms of both scale and opportunity to make progress on cancer. Over one million Indians are diagnosed with cancer each year, and new cases are expected to rise to 1.7 million by 2035. Today, fewer than 30% of Indian cancer patients survive for five years or more after their diagnosis: a mortality rate disproportionately higher than across the rest of the world. It has the third highest number of cancer cases in the world and the second highest number of cancer deaths. Addressing this burden has become an area of priority for the Government of India, with the development of affordable approaches to fighting cancer at the top of its agenda.

Following consultation with leading researchers in both India and the United Kingdom, and a visit by Prime Minister Modi and the then Prime Minister May to the Francis Crick Institute in April 2018, CRUK and the Government of India's Department of Biotechnology (DBT) agreed to partner for a £10 million, five-year bilateral research initiative. The theme of affordable approaches to cancer was selected in response to growing global challenges related to affordability of cancer prevention and care, and the potential to make significant progress against cancer outcomes. Building on specific areas of scientific opportunity in India and the United Kingdom, the initiative focuses on prevention, early detection, diagnosis and treatment, and is likely to include large-scale population studies, development of new technologies and research into re-purposing existing drugs.

In March 2019, the India-United Kingdom Advisory Panel finalized the initiatives' research challenges that cover a range of issues in affordability and formed the basis for a funding call. A total of seven bilateral teams have now been awarded seed funding grants and, despite the impact of the COVID-19 pandemic, have made significant progress. Challenges such as travel restrictions and being unable to access laboratories have been problematic, but teams have been utilizing virtual technology to ensure they are in regular contact and can develop their projects. Several have been able to recruit new institutes into their studies, along with expanding their collaborations in both India and the United Kingdom, to include further expertise.



Meeting between Prime Minister Modi and then Prime Minister May in 2018 to discuss affordable cancer care

Furthermore, teams have been conducting patient and public engagement through online events supported by specialists in this area along with promoting their projects at international research conferences. One team have had strong interest in their study from a global group of gynaecological cancer specialists and other countries may be added to their study in the future. This progress highlights the determination of the teams to meet their research aims and the importance of this initiative for developing much needed affordable approaches to cancer. The hope is that, by bringing together the complementary strengths of India and the United Kingdom, the initiative will accelerate progress in research that will impact cancer outcomes on a global scale.

Lessons from CRUK's global engagement

CRUK is a charity that has traditionally focused on the cancer pathway in the United Kingdom, and its adaptation to a global setting has been a complex and incremental process that continues to evolve. This has been facilitated by the identification and development of relationships with local partners and a range of cross-sectoral actors already active in global health and development, to ensure collaboration and complementarity on shared objectives, as well as sustainability. Further lessons learned so far include:

- ➔ There is space and need for new thinking on global cancer control, in particular to reach new audiences and collaborate on high profile agendas, such as the SDGs and Universal Health Coverage, and to reflect the interplay between communicable and noncommunicable disease, which COVID-19 has so starkly illuminated.
- ➔ Global political trends affect seemingly straightforward ambitions. On tobacco control, the unpopularity of

development assistance among many donor country populations and government reticence to increase and earmark taxes both significantly affect what is achievable on tobacco taxation.

- ➔ Understanding national ecosystems is key. Low- and middle-income countries have distinct contexts and challenges, albeit with regional trends that present opportunities for wider geographic impact. It is not possible to make a meaningful policy intervention without understanding the wider factors influencing governance.
- ➔ Influencers and ambassadors could be more regularly identified and utilized. High profile champions for specific issues have the potential to cut through and be heard by governments, on behalf of civil society actors.
- ➔ Sustainable funding is a challenge to the whole global health agenda – although noncommunicable diseases suffer from particularly chronic underfunding. The most realistic and potentially achievable approach is to build and maintain salience around pressing issues, while mainstreaming where possible into existing development funding systems. ■

Bekki Field leads the international cancer prevention programme at Cancer Research UK, which supports tobacco control and cervical cancer prevention efforts in low- and middle- income countries through policy research grants and advocacy. Prior to this, she spent a decade in the British diplomatic service and was posted to the UK Representation to the European Union, and the UK Delegation to the Organisation for Security and Cooperation in Europe, based in Vienna.

Caroline Mitchell, Research Grants & Communications Officer, India-UK Cancer Research Initiative

Caroline Mitchell is a Research Grants and Communications Officer in the International Partnerships team at Cancer Research UK and works on the India-UK Affordable Approaches to Cancer Initiative.

Prior to Cancer Research UK, Caroline spent time working in Uganda for a youth-led development charity before joining an international development charity, based in Scotland, that focuses on growing businesses in developing economies through providing training and consultancy.

“Achieving policy change in low- and middle-income countries on issues like tobacco tax is tough. It is inherently political and rarely achieved by outside organizations alone. That is why CRUK has been pioneering a combination of local insight – think tanks who understand how things really get done in their countries – and specialist international support. In Sri Lanka and Nepal this is beginning to pay dividends. New organizations, plugged into local politics and well positioned to influence change, are establishing themselves as new players in the tobacco control world.”

Will Paxton, Director and founder, Kivu International



Special report on the inaugural London Global Cancer Week, 24–28 November 2019

Global Health Dynamics, publishers of *Cancer Control*, was delighted to be media partner for the first London Global Cancer Week which took place in November 2019. The following report has been prepared by the Steering Group of the London Global Cancer Week on what proved to be an exciting and informative event. The Week brought together key members of the cancer community from all around the world to address the problems of cancer care in low- and middle-income countries both through presentations and discussion.

Historically the United Kingdom has had a significant influence on the global development of disease control strategies and scientific method. The UK Government played a major role in designing the architecture of the MDGs which effectively excluded cancer and the other noncommunicable diseases during the period 2001–2015. Despite this, many productive formal and informal partnerships and strategic relationships were forged between UK Royal Colleges, universities, private sector organizations, cancer centres and NGOs and their counterparts in low- and middle-income countries (LMICs). In recent years, amidst a proliferation of “global health” institutes and departments in UK Universities, the Oncology Section of the Royal Society of Medicine (RSM) has hosted an annual meeting in November focused on issues around cancer in LMICs. Its audience has been primarily clinicians and health professionals that have an academic interest or clinical involvement in “global health”. In the same month *The Economist* Events Unit’s (EEU) War on Cancer – Europe programme has provided a platform for a day of discussions with a different type of speaker and attendees: policy makers; CEOs and international thought leaders.

When in November 2018 these meetings took place on succeeding dates (RSM: 19 November 2018; EEU: 20 November 2018) and had met with success, it was evident that an opportunity existed to create a series of co-ordinated events under the umbrella title “London Global Cancer Week” that could should provide a 360° picture of the impact of the rising incidence of cancer in LMICs. Such an initiative offered the opportunity to take stock of the challenge cancers represents to the emerging countries and to highlight how UK partners can continue to help LMICs address the rising tide of malignant disease.

It was evident that other institutions would need to be approached in order to cater for different types of audiences.

Informal discussions with colleagues at the Centre for Global Health Security at The Royal Institute of International Affairs, Chatham House, were immediately productive: Chatham House would consider hosting two meetings: a closed Round Table discussion on “cancer in an age of universal health coverage” and an open members’ event on “toxic air pollution and cancer”. With the pre-existing plans of the RSM and EEU meetings this provided a third day of events.

An ad hoc Steering Group (SG) was formed which prioritized the importance of securing sufficient funding for a project manager and a coordinated communications strategy that included high social media activity. A concept note was commissioned to support the search for potential sponsors and for additional organizations that might be interested in hosting a LGCW event. This helped clarify the purpose of the London Global Cancer Week, which would be to:

- ➔ draw attention to the global cancer pandemic;
- ➔ provide an opportunity for multisectoral/multidisciplinary discussions, engagement and reflection on the costs and challenges arising from the spread of cancer in LMICs and what it will take to address the growing cancer burden;
- ➔ highlight opportunities for the UK to contribute towards building capacity for sustainable cancer control in LMICs through training, research, aid and diplomacy;
- ➔ be a catalyst for the development of substantial multilateral and bilateral initiatives in global cancer control and research;
- ➔ explore how governments and civil society can address the commercial determinants of health that adversely impact on cancer prevention and control.

It was agreed that the week of events would run from Sunday 24 November to Thursday 28 November, 2019, and that the schedule of events should be coordinated so as to

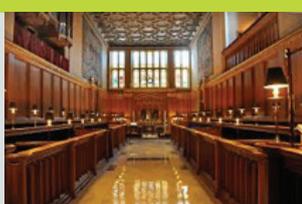
avoid clashing of dates and timings. Theoretically, a visitor to London would be able to attend every open meeting if he /she needed to. Crucially it was also agreed that each event host would be responsible for their own costs and PR; in return the LGCW organizers would promote their event on the LGCW website and would not ask for a financial contribution to support LGCW umbrella activities.

The Steering Group recognized that helping event organisers attract important international speakers would contribute to raising the profile of the Week. Following her stirring address at the United Nations High Level Meeting on Noncommunicable Diseases the previous year (September 2018, UN, New York) an approach was made to HRH Princess Dina Mired in her capacity as the President of the Union for International Cancer Control (UICC). Princess Dina generously agreed that she would fly from Jordan to London to support London Global Cancer Week and to attend as many LGCW events as she was able on the condition that she would be given an opportunity to address the issues that were of global importance. The Princess's participation was warmly welcomed by the event hosts, most of whom were able to invite her onto their meeting agendas as a key note speaker.

DAY ONE – Sunday 24 November

Service of Sung Mattins and Reception

Host: The Church of England
Venue: The Chapel Royal
St James's Palace, London SW1
Time: 11.15 am – 1.30 pm



Thirty-one people, including four international speakers, members of the London Global Cancer Week Steering Group and representatives of UK charities attended the service of Sung Mattins at the Chapel Royal, St James's Palace as guests of the Church of England. They were welcomed by Dr James Newcome, Bishop of Carlisle and were privileged to enjoy the matchless singing of the Chapel Royal Choir. At the conclusion of the Service Canon Paul Wright (Sub-Dean of the Chapel Royal) thanked the LGCW guests for their attendance and shared some interesting facts about the Chapel Royal before guiding the group towards York House. At the Reception Mark Lodge gave a short address, thanking Bishop James and Canon Paul for their kindness and the Church of England for its generosity. Welcoming the international speakers to London, he briefly summarized the objectives of the London Global Cancer Week and wished the speakers and the organizers good fortune in the week that lay ahead.

DAY TWO – Monday 25 November

Cancer control in low- and middle-income countries: New solutions to evolving challenges

Host: Royal Society of Medicine
Oncology Section
Venue: Royal Society of Medicine,
1 Wimpole St, London, W1
Time: 9.00 am – 5.30 pm



In a full day's meeting 21 experts (eight from the UK, 13 international) contributed 14 talks, presentations and workshops. Several speakers spoke of their experiences collaborating with LMICs with the aim of improving outcomes. The topics addressed ranged across the cancer spectrum from the challenge of falsified medicines (Chloe Tuck, Sheffield University, UK), and the necessity of developing resource-stratified guidelines for oncology in LMICs (Dr Benjamin Anderson, University of Washington, USA) to the damaging stigma encountered by women with breast cancer in LMICs (Dr Beatrice Waife Addei, Kumasi, Ghana) and the important role of primary care in global oncology (Dr Ophira Ginsburg). The annual Vanessa Moss prize was presented by HRH Princess Dina Mired to the winner Dr Nono Ahuka from Congo (in absentia) for his work on raising awareness of prostate cancer in sub-Saharan Africa. HRH Princess Dina went on to give an inspiring talk on "The need for a new paradigm shift on building sustainable partnerships and solutions to tackle cancer control challenges in the low- and middle-income countries", before formally launching the first London Global Cancer Week.

Delegate feedback collected on the day was overwhelmingly positive. Quotes from attendees include that the day was "inspiring" and provided "an excellent networking opportunity". The majority of attendees felt that knowledge gained from the conference would impact on their practice. A call and subsequent momentum for the setting up of a national global oncology network has come from this meeting.

DAY THREE – Tuesday 26 November

War against cancer – Europe

Host: Economist Events
Venue: Waldorf Hilton Hotel,
London WC2
Time: 8.45 am – 6.15 pm



Over the last four years, *The Economist Events'* series of cancer summits in Europe has articulated the challenges and opportunities in improving cancer control. There is still considerable unmet patient and societal need; cancer control

and preparedness varies among and within countries; and investment and health systems generally lag behind the advances in technology and services available to combat cancer. The way forward can seem dauntingly complex. The 2019 summit looked at the solutions, not problems.

Building on the findings of *The Economist* Intelligence Unit's recently released Index of Cancer Preparedness, the summit explored examples and case studies from programmes that have navigated the complexities to genuinely "move the needle" on cancer control. It set out to celebrate the successes – even if these were small-scale at present – in areas of policy, regulation, investment, partnerships, systems and technology that had led to better outcomes for patients, and to ask: What was accomplished? How? And how could this progress be built upon? It was clear from the presentations and discussions that there was still a long way to go before the inequities of care would be eliminated and the stigma and misconceptions around cancer were removed.

DAY FOUR – Wednesday 27 November

Cancer in an age of universal health coverage

Host: Royal Institute of International Affairs
Venue: Chatham House, 10 St James's Square, London SW1
Time: 1.00 pm – 4.00 pm



The primary purpose of this roundtable was to bring together leading cancer experts, advocates and leading figures from the universal health coverage (UHC) movement and global health, to highlight the importance of prioritizing cancer services in the UHC reform process. The event featured participants from many contexts, including patient advocates, donor organizations, global advocates and leading experts on cancer and key figures in the global health field. The meeting was held under Chatham House Rules.

Tackling toxic air pollution in cities

Host: Royal Institute of International Affairs
Venue: Chatham House, 10 St James's Square, London SW1
Time: 6.00 pm – 8.00 pm



Participants: Camilla Hodgson, Environment Reporter, *Financial Times*; Dr Benjamin Barratt, Senior Lecturer in Chinese Environment, Kings College London; Dr Susannah Stanway, Consultant in Medical Oncology Royal Marsden NHS Foundation Trust; and Elliot Treharne, Head of Air Quality,

Greater London Authority. Chair: Rob Yates, Head, Centre on Global Health Security, Chatham House.

Air pollution has been classified as a cancer-causing agent with evidence showing an increased risk of lung cancer associated with increasing levels of exposure to outdoor air pollution and particulate matter. Air pollution is also known to increase risks for other diseases, especially respiratory and heart diseases, and studies show that levels of exposure to air pollution have increased significantly in some parts of the world; mostly in rapidly industrializing countries with large populations.

In coordination with London Global Cancer Week partner organizations, this Chatham House Members Event outlined the evidence linking air pollution and cancer rates in London and other major cities. Panellists provided a comprehensive picture of the impact of the rising incidence of cancer across the world, the challenges the cancer pandemic poses to the implementation of universal health coverage and the existing UK contribution to strengthening capacity in cancer management and research in developing countries.

DAY FIVE – Thursday 28 November

Cancer screening in a middle-income country: The idealist versus the pragmatist

Host: C3 Collaborating for Health
Venue: CAN Mezzanine, 7-14 Great Dover Street London, SE1
Timing: 8.30 am – 10.00 am



Dr Feisul Mustapha, Consultant Public Health Physician and Deputy Director (NCDs) at the Ministry of Health Malaysia described how, historically, delays in presentation have been commonly found among cancer patients most developed and developing countries, Malaysia is experiencing an epidemiological transition where noncommunicable diseases (NCDs) in particular cardiovascular diseases and cancers have progressively become more prevalent. In cancer, early detection and prompt treatment improves the chances of cure. Almost 60% of cancers in Malaysia are detected late (stage III and IV) despite the availability and accessibility of cancer screening. Although the core concepts of cancer prevention and control programmes should be applied universally, implementation of screening programmes in a middle-income country such as Malaysia requires distinct considerations. It must be an iterative process with realistic interventions taking into consideration cultural values and belief systems, beyond healthcare systems. Working in a resource-constrained setting, yet with the involvement of various stakeholders and players, Dr Feisul Mustapha described how Malaysia is moving

forward and will continue to engage new partners for potential collaborative work to address the various challenges.

**Cancer in the Commonwealth:
The case for collective action
on cervical cancer**

Host: Commonwealth
Secretariat
Venue: Marlborough House
Pall Mall, London SW1
Timing: 10.30 am – 1 pm



Under the heading Health officials urge action amidst rising cancer cases in Commonwealth the Commonwealth Secretariat released the following report:

29 November 2019

Leading health officials are calling for urgent action to reduce the number of cancer cases in the Commonwealth, which are above global averages. Cancer rates in the Commonwealth have risen by 35% over the past decade, including three of the most common forms: breast, cervical and prostate cancer.

This analysis was presented at a Commonwealth event as part of the first London Global Cancer Week. Attendees included officials from high commissions, academic institutions, health organisations and development agencies. In 2018, around three million cancer cases were reported in the Commonwealth, equivalent to one new case in every 10 seconds. Of those three million cases, about 1.7 million people died, equivalent to one death every 18 seconds. The analysis predicts a further 35% rise in the incidence of cancer by 2030. Health officials have therefore urged governments to realign their health priorities to provide training and improve access to early detection and treatment of tumours.

Professor Isaac Adewole, a specialist in female cancer and former Nigerian Minister of Health, presented the Commonwealth's collective action on cervical cancer. "I want Commonwealth leaders to declare war on cervical cancer. It is almost 100% preventable," he said. "The most efficient formula for cervical cancer prevention is a combination of two strategies: vaccination plus screen and treat. The prevention and defeat of cervical cancer is a challenge worthy of the Commonwealth and is well within its capabilities, as demonstrated by the collective global action on reducing persistent, high levels of maternal mortality, which has been a success."

It is estimated that without collective action, cervical cancer deaths will rise by 62% by 2030 causing one death every three minutes in the Commonwealth. The analysis highlights the worrying impact of cancer on productivity. In 2015, cancer accounted for more than 200 million work days lost worldwide due to people missing work to attend medical appointments.

"Cancer is not just a health issue, it is also a development issue," said Deputy Secretary-General Arjoon Suddhoo at the event. He added: "We are working on developing a Commonwealth price-sharing and information-sharing database for essential medicines such as the HPV vaccine. The database will help member countries improve citizens' access to prevention approaches and negotiate fair prices for the human papillomavirus (HPV) vaccine, which helps protect teenage girls against cervical cancer."

The analysis identifies tobacco, excessive alcohol consumption, poor diet, lack of exercise and obesity as the five major cancer risk factors. Prevention of these factors, the report shows, could reduce cancer incidences.

"It is all about the political will," said Princess Dina Mired of Jordan, immediate past President of the Union for International Cancer Control. "If leaders decide to focus on health, it will bring hope. We see it actually happening in Rwanda which has provided universal health coverage to 90% of its citizens and that by public funding."

The analysis also reveals that a longer duration of ultraviolet rays has increased cancer incidences and the indirect effect of climate change has disrupted the delivery of health services, particularly in small island states. Officials recommended people to carry out regular screenings to help detect early signs of the diseases which they said, "raises the chances of survival."

**Oncology in the global setting:
Improving access to quality
radiotherapy and radiology**

Host: Royal College of
Radiologists
Venue: 63 Lincoln's Inn Fields,
London, WC2
Timings: 1.30 pm – 5.30 pm



Hosted by the Royal College of Radiologists, this global cancer event provided the chance to hear from innovative individuals who are improving cancer services in LMIC settings. Globally, diagnostic radiology and radiotherapy are essential components of cancer management. Imaging is required in virtually all cases, while radiotherapy is an essential but sometimes forgotten modality of cancer treatment. It is estimated that approximately half of new cancer patients should receive radiotherapy as part of their curative treatment. Despite the key role of radiology and radiotherapy there is a paucity of functional services and infrastructure outside of high-income settings. The Royal College of Radiologists may play a key role in improving equitable access to cancer treatment as it offers both credibility and a rich resource of expertise.

Outcomes of London Global Cancer Week 2019

London Global Cancer Week fulfilled its primary purpose of drawing attention to the global cancer pandemic and providing the opportunity for multisectoral/multidisciplinary discussions, engagement and networking. During the Week, expert speakers reflected on the costs and challenges arising from the spread of cancer in LMICs and what it will take to address their growing global cancer burden. Presentations highlighted UK-LMIC partnerships that were building capacity for sustainable cancer control in the emerging countries through training and research.

There were three immediate outcomes of the inaugural London Global Cancer Week.

Commonwealth support

In her Sky TV interview on World Cancer Day (4 February, 2020) the Commonwealth Secretary General Baroness Patricia Scotland QC restated the case for supporting collective action on the elimination of cervical cancer that had been presented at the Marlborough House meeting on 28 November 2019.



"We know that if we don't do something together it is likely in the next ten years there will be a further 35% rise (in Commonwealth cancer incidence). And so the Commonwealth health ministers came together last year in May, and they are going to come together again this May, to say "What can we do about it? How can we share the knowledge? How can we make sure that what works and what doesn't work gets to be transferred? And the great news is... that cervical cancer is preventable. We have seen that in Australia, but we have also seen that in the developing country of Rwanda. Making the knowledge available, making the vaccine available has... virtually eradicated cervical cancer in those two countries. So they are exemplars of what we can do if we work together and share the best practice and actually get these prices down in terms of the HPV vaccine. We know that it works but we've got to start early and there's a lot that we can do. And the Commonwealth is absolutely committed to doing it."

Visit to Ghana

As a result of the presentations that had highlighted the negative impact of cancer stigma on the early presentation of cancer – particularly women of African heritage? with breast and cervical cancer in both developed and developing countries – Dr James Newcome, The Anglican Bishop of Carlisle and Mark Lodge (Executive Director, international Network for Cancer Treatment and Research UK) were invited by Dr Beatrice Waife Addei, the President of Breast



Care International to visit Kumasi, Ghana, and to address church leaders and their congregations on the importance of early presentation. During their three-day visit, which was widely reported in the Ghanaian media, Dr Newcome met with the clinical staff at the Peace and Love Hospital, Kumasi, was interviewed on local radio about the importance of spirituality to cancer care and preached a sermon at St Cyprian's Anglican Cathedral at which he spoke out about the danger of erroneous teachings and of predatory pastors who preyed on the fears of families of cancer patients.

Development of the UK Global Cancer Network

Moves have begun towards establishing a UK network of individuals and institutions involved in cancer global health that will strengthen existing UK-LMIC partnerships and build upon the momentum generated by the success of London Global Cancer Week. Dr Susannah Stanway, Professor Richard Cowan and Mark Lodge have formed a core group that are reaching out to active participants in LGCW 2019. The inaugural meeting of the UK Global Cancer Network will take place on Sunday 15 November 2020. Further details are available on the London Global Cancer Week website www.lgcw.org.uk

London Global Cancer Week, 15-20 November 2020

The COVID-19 pandemic has become a major disrupter of plans, requiring the widespread introduction of social distancing and causing the postponement of the NIHR 2020 Research and Improvement Conference (UK), World Cancer Congress (Oman), Commonwealth Heads of Government Meeting (Rwanda) and other key events. London Global Cancer Week is no exception and the 2020 meeting will be held virtually between 15–20 November 2020. The programme is set out below; for further details visit: www.lgcw.org.uk.

Schedule of online events

Sunday 15 November

11.15 am – 12.30 pm
2.30 pm – 5.30 pm

Mattins Service, Chapel Royal, St James's Palace
UK Global Cancer Network: Exploratory meeting

Monday 16 November

8.00 am – 9.00 am
9.00 am – 11.00 am
11.00 am – 1.00 pm
1.00 pm – 5.30 pm

African Organisation for Research and Training in Cancer (AORTIC) *Cancer in Africa*
United Nations (IAEA, IARC): UN Global response to cancer
World Health Organization: WHO initiatives in cancer
Royal Society of Medicine Oncology Group: The impact of COVID-19 on cancer management in low- and middle-income countries

Tuesday 17 November

9.30 am – 3.30 pm
3.30 pm – 5.30 pm

UK ONS: The Global Power of Oncology Nursing
GCPA-Europe/SIDCER/INCTR: Research and Treatment of Paediatric Cancers During Covid-19: Global Perspectives

Wednesday 18 November

8.00 am – 10.00 am

10.00 am – 10.45 am

10.45 am – 12.45 pm
1.00 pm – 3.00 pm
3.00 pm – 5.00 pm

6.00 pm – 7.00 pm

London School of Hygiene and Tropical Medicine: International breakfast webinar – Global surveillance of cancer survival CONCORD programme
Alliance Mondiale Contre Le Cancer: Reference centre for the diagnosis of childhood cancers in Senegal
African Cancer Registry Network: Cancer Surveillance in Africa
The Lancet Oncology: The Lancet Childhood Cancer Commission
LACOG / SLACOM / The Lancet Oncology: Emerging technologies and clinical research in Latin America
Royal Institute of International Affairs: Chatham House Members Event – Making the case for cancer control and prevention

Thursday 19 November

7.00 am – 8.15 am
8.30 am – 10.00 am

10.00 am – 12.00 pm
12.00 pm – 2.00 pm
2.00 pm – 4.00 pm

Eastern Mediterranean NCD Alliance: Cancer in the Eastern Mediterranean
C3 Collaborating for Health International: Breakfast Webinar Cancer Prevention with HRH Princess Dina Mired and Dr Bronwyn King
Commonwealth Secretariat: Cancer Prevention Session #1
UICC: Antimicrobial Resistance (AMR) and Cancer
Commonwealth Secretariat: Cancer Prevention Session #2

Friday 20 November

1.30 pm – 3.00 pm

3.00 pm – 5.00 pm

US National Cancer Institute Center for Global Health: International Collaboration to Advance Global Cancer Research and Control: The US National Cancer Institute Perspective
Two Worlds Cancer Collaboration (INCTR Canada): Bridging the cancer divide between two worlds – collaboration and partnership

Regional Reports: Africa Focus

38 Towards a reference centre for the diagnosis of childhood cancers in Dakar, Senegal

Professor Martine Raphaël, Vice-President, Alliance Mondiale Contre le Cancer (AMCC), France; **Professor Awa Toure**, Head of Haematology Laboratory, Aristide Le Dantec University Hospital, Cheikh Anta Diop University, Dakar, Senegal; **Professor Cherif Dial**, pathologist, Idrissa Pouye de Grand Yoff General Hospital, Cheikh Anta Diop University, Dakar, Senegal; **Professor Abibatou Sall**, MD, PhD, Haematologist, Dalal Jamm University Hospital, Cheikh Anta Diop University, Dakar, Senegal; **Dr Fatou Bintou Diagne**, paediatric oncologist, Aristide Le Dantec University Hospital, Cheikh Anta Diop University, Dakar, Senegal; **Dr Fatimata Bintou Sall**, haematologist, Aristide Le Dantec University Hospital, Cheikh Anta Diop University, Dakar, Senegal; **Professor Aurore Coulomb**, Head of the Pathology Department, Armand Trousseau/La Roche Guyon University Hospital, AP-HP, Sorbonne University, Paris, France; **Dr Elisabeth Auberger**, pathologist, Simone Veil Hospital, Eaubonne, France; and **Dr François Desbrandes**, Head of the “My Child matters” childhood cancer programme, Sanofi Espoir Foundation in Paris, France

42 Understanding breast cancer survivorship in Tanzania

Dr Nazima J Dharsee, Ocean Road Cancer Institute, Dar es Salaam, Tanzania and **Professor Theresa Wiseman**, The Royal Marsden NHS Foundation Trust, University of Southampton, UK

46 Cancer control in sub-Saharan Africa and its impact on health systems strengthening: A case study from Ghana

Dr Beatrice Wiafe Addai, Chief Executive Officer and Senior Medical Officer, Peace and Love Hospitals in Accra and Kumasi, Ghana

49 Diagnostic imaging challenges to the poor on the long road to the cancer centre

Dr Elizabeth Joekes, Co-founding Director, Worldwide Radiology and Consultant Radiologist, Liverpool University Hospitals Foundation Trust, UK, and **Dr Sam Kampondeni**, Neuroradiologist, Queen Elizabeth Central Hospital, Blantyre, Malawi

53 Using the African Digital Health Library for cancer control: Dissemination of African cancer research output

Christine Wamunyima Kanyengo, Librarian, University of Zambia; **Dr Grace Ada Ajuwon**, Principal Librarian, E Latunde Odeku Medical Library, College of Medicine, University of Ibadan, Nigeria; **Abdrahamane Anne**, Medical Librarian, Faculty of Medicine, University of Bamako, Mali; **Muziringa Masimba**, Health Librarian, formerly at University of Zimbabwe; Nancy Kamau university librarian, Kenya Methodist University, Kenya; **Justin Maranga Merande**, Head of Electronic Resource Training, College of Health Sciences Library, University of Nairobi Library, Kenya; **Nason Bimbe**, software developer; **Mercy Wamunyima Monde** Librarian, School of Medicine, University of Zambia; **Celine Maluma Mwafuilwa**, Librarian, Medical Library, University of Zambia; **Mark Lodge**, Executive Director, International Network for Cancer Treatment and Research UK; **Becky Lyon**; **Julia Royall**, Principal Investigator, African Digital Health Library

Towards a reference centre for the diagnosis of childhood cancers in Dakar, Senegal

Professor Martine Raphaël (top left), Vice-President, Alliance Mondiale Contre le Cancer (AMCC), France; **Professor Awa Toure** (top middle), Head of Haematology Laboratory, Aristide Le Dantec University Hospital, Cheikh Anta Diop University, Dakar, Senegal; **Professor Cherif Dial** (top right), pathologist, Idrissa Pouye de Grand Yoff General Hospital, Cheikh Anta Diop University, Dakar, Senegal; **Professor Abibatou Sall** (middle left), Haematologist, Dalal Jamm University Hospital, Cheikh Anta Diop University, Dakar, Senegal; **Dr Fatou Bintou Diagne** (middle), paediatric oncologist, Aristide Le Dantec University Hospital, Cheikh Anta Diop University, Dakar, Senegal; **Dr Fatimata Bintou Sall** (middle right), haematologist, Aristide Le Dantec University Hospital, Cheikh Anta Diop University, Dakar, Senegal; **Professor Aurore Coulomb** (bottom left), Head of the Pathology Department, Armand Trousseau/La Roche Guyon University Hospital, AP-HP, Sorbonne University, Paris, France; **Dr Elisabeth Auberger** (bottom middle), pathologist, Simone Veil Hospital, Eaubonne, France; and **Dr François Desbrandes** (bottom right), Head of the “My Child Matters” childhood cancer programme, Sanofi Espoir Foundation, Paris, France



In order to reduce the healthcare gap in childhood cancers between high-income and low-middle-income countries, as has been strongly encouraged by the World Health Organization (WHO) since 2018, a Reference Centre for the Diagnosis of Childhood Cancers will be developed in Dakar, Senegal, to provide accurate diagnoses. This ambitious project has the overall goal of developing high-quality morphology, immunophenotyping, molecular biology and cytogenetics expertise in order to improve access to timely and accurate diagnoses of childhood cancers on the basis of WHO criteria. This project benefits from the involvement of local institutions, the faculties of medicine, university hospitals, the nongovernmental organization Alliance Mondiale Contre le Cancer (AMCC) and the Sanofi Espoir Foundation.

Each year, 200,000 to 300,000 new childhood cancer cases are diagnosed worldwide. In 2018, the World Health Organization (WHO) made a priority of managing these cases through the Global Initiative for Childhood Cancer (GICC). The GICC drew attention to the gap in managing childhood cancer between high-income countries and low- and middle-income countries (LMICs), where 80% of cases occurred with only a 20% or less survival rate. In contrast, more than 80% of children are cured in high-income countries. The WHO-GICC target for LMICs (1) is to attain at least a 60% survival rate for children with cancer by 2030. Limited access to healthcare includes a lack of capacity in cancer diagnosis, treatment difficulties and abandonment, and a low level of palliative care availability.

In Senegal, a West African country with 16,209,125

inhabitants and 50% of the population aged under 20, about 200 cases of childhood cancers have been reported per year. The same demographic situation can be observed throughout the West African sub-region. About half of the population lives around the capital city of Dakar. The French NGO, GFAOP (Groupe Franco-Africain d'Oncologie Pédiatrique) manages a pilot unit in Senegal, as in other Francophone Africa countries, to treat children with cancer. The Sanofi Espoir Foundation, through its “My Child Matters” programme, provides part of the funding (2).

However, in addition to the critical figures for the treatment of children with cancer, there are difficulties in diagnosis using the WHO criteria due to a lack of equipment, reagents and training in diagnostic laboratory work. The Alliance Mondiale Contre le Cancer (AMCC), the French branch of the

International Network for Cancer Treatment and Research (INCTR), promotes several programmes, such as a pathology programme that includes telepathology, with funding to set up additional techniques for diagnosis and research (3).

One of the aims of the AMCC pathology programme is to develop and improve the quality of tumour diagnosis, especially for childhood cancer. This aim will be part of the project to establish a Reference Centre for the Diagnosis of Childhood Cancer in Dakar, Senegal (Centre de Référence pour le diagnostic des Cancers de l'Enfant, CRDCE, Dakar, Senegal) with the support of the Sanofi Espoir Foundation "My Child Matters" programme. The overall project goal is to develop the cytological, histological, immunological, molecular and genetic diagnosis of childhood cancer according to the criteria defined by WHO, with the aim of improving survival rates for children with cancer in LMICs in French-speaking Africa by developing timely and accurate diagnoses. This project will be spread over two phases. The first phase, taking place over 18 months, includes the following specific objectives:

- ➔ Improve the sample flow and shorten diagnostic delays through optimal sampling and result management.
- ➔ Upgrade the paediatric anatomy and cytopathology department to improve morphological standards, a prerequisite for obtaining second opinions via telepathology.
- ➔ Implementation of complementary immunological techniques for diagnosis according to the WHO criteria by providing the reagents for these techniques on the basis of immunohistochemistry and flow cytometry.
- ➔ Provide technical training and expertise for African specialists over the longer term by establishing university degrees in anatomy and cytopathology in paediatric oncology.
- ➔ Encourage research at different levels – clinical, epidemiological and fundamental research – by providing equipment for sample banks (cells, tissues, plasma, DNA and RNA) and software to process epidemiological data.

The cytogenetic platform and the molecular biology lab will be developed under second phase (2022–2024) of this project.

The CRDCE will be established as a federation between the various services of the Cheikh Anta Diop University of Dakar (UCAD) and the haematology laboratories from two university hospitals - the Aristide le Dantec and the Dalal Jamm. A clinical research coordinator will be responsible for specimens and results management, and for coordinating diagnostic activities and links with clinicians. There is an existing agreement (*Accord de Coopération*) between the Faculty of Medicine, Pharmacy and Odontology-Stomatology (FMPOS) departments at the

University Cheik Anta Diop (UCAD) in Dakar and the AMMC, with the aim of coordinating activities between the Aristide Le Dantec and Dalal Jamm university hospitals, the FMPOS Faculty and the AMCC, which is supported by the Sanofi Espoir Foundation "My Child Matters" programme.

The UCAD anatomy and cytopathology service will be upgraded and the haematology laboratory will be equipped with a microscope and a digital camera to use telepathology via the i-Path/INCTR platform (3, 4). The current telepathology function using the i-Path platform will be extended to the existing network of 20 centres spread throughout Francophone Africa, including sub-Saharan Africa and the Maghreb. Telepathology enables the sharing of comments on consultation cases and second opinions on difficult cases, as well as for patients enrolled in clinical trials. The exchanges between South/North experts - and henceforth between South/South experts - will help decrease the effects of geographical remoteness (5-9).

The Dalal Jamm Hospital haematology laboratory is working with the hospital administration to develop flow cytometry. The cytometer will be provided, and this project will help obtain the reagents needed to start flow cytometry immunophenotyping to characterize haematological malignancies (10,11). In the UCAD pathology laboratory, under the responsibility of the pathologist, immunohistochemistry techniques will be developed to characterize solid tumours in childhood cancers.

The training aspect will be first developed in the field of telepathology, by providing comments on difficult cases, and then at technical levels once additional techniques have been set up, including immunohistochemistry and flow cytometry, and also in connection with the GFAOP e-learning programme which will provide courses and tutorials.

Research has been carried out by AMCC programmes since LMICs were first identified (12), and covers clinical, biological, epidemiological and fundamental activities. It is one of the reasons behind developing centralized sample libraries in UCAD and the university hospitals from the beginning, and the development of software using epidemiological data.

This Reference Centre, where complementary techniques, immunohistochemistry and flow cytometry will be developed during the first phase, will in due course be made available to other countries from West and Central Francophone Africa sub-regions, as well as to the pilot units of the GFAOP. This will constitute the first experience of sharing South/South samples for complementary techniques between sub-Saharan African countries.

The sustainability of the first phase of the project will be the most important criterion for launching the second phase, with the aim of creating a molecular biology laboratory and

a cytogenetic platform. Measurement indicators will be integrated at the end of the first phase of the project, including:

- ➔ The development and sustainability of the complementary techniques of immunohistochemistry and flow cytometry.
- ➔ Analysis of diagnosis accuracy and the concordance between initial and final diagnoses using telepathology by the kappa coefficient.
- ➔ The time needed between the arrival of the samples, morphological diagnosis, and complementary techniques.
- ➔ Proposals for research projects and links to the university, such as MD and PhD theses.
- ➔ The number of cases communicated by sub-Saharan Africa countries, especially from the West Africa sub-region, but also from the GFAOP pilot units and Central Africa.

Finally, this ambitious project covers all the steps needed to obtain the most accurate diagnosis of childhood cancer according to the WHO criteria, with shorter delays between sampling and results. This federation is coordinated by a clinical research coordinator linked closely to paediatric oncology departments, diagnosis laboratories, hospitals, and the university. It will also become available to other hospitals in the country as well as to other countries in the sub-region. Additionally, the GFAOP pilot units match the aims of the WHO Global Initiative on Childhood Cancer to expand in-country capacity to deliver best practices in childhood cancer care. ■

Acknowledgements to Professor Abdoulaye Samb, Dean of the Faculty of Medicine, Pharmacy and Odonto-Stomatology (FMPOS) of Dakar for his support.

Professor Martine Raphaël, MD, PhD, is Vice-President of the Alliance Mondiale Contre le Cancer (AMCC), France. She has been Professor of Haematology (1997–2012), Head of the Haematology Department of the Faculty of Medicine and University Hospitals of Paris-Sud (2003–2012) and Emeritus Professor, University Paris-Sud (2012–2018). Professor Raphaël was President of AMCC (2013–2019) and Vice-President since 2019. She is an Officer of the Légion d'Honneur. Since the 1980s, she has been involved in the diagnosis of lymphomas in low- and middle-income countries, especially in Africa, and in the development of telepathology in Francophone Africa using i-Path/INCTR.

Professor Awa Toure, MD, PhD, is a haematologist at the Aristide Le Dantec University Hospital in Cheikh Anta Diop University, Dakar, Senegal, where she is Professor of Haematology and Head of the Haematology Laboratory at the Aristide Le Dantec Hospital. Previously, she was Head of the Biology Department at the Faculty

of Medicine at Cheikh Anta Diop University (2012–2016). Her main topic of research is hemostasis in the field of thrombosis risk factor.

Professor Cherif Dial, MD, is a pathologist at the Idrissa Pouye de Grand Yoff General Hospital, Cheikh Anta Diop University, Dakar, Senegal. He is a referring pathologist for paediatric tumours and a member of the Anatomy and Cytopathology Committee of the French African Group for Paediatric Oncology (GFAOP).

Professor Abibatou Sall, MD, PhD, is a haematologist at the Dalal Jamm University Hospital, Cheikh Anta Diop University, Dakar, Senegal. She has 15 years of experience in haematology laboratories. From 2018, she has been Professor of Haematology at Cheikh Anta Diop University. Previously, she was Head of the Haematology Laboratory and the Blood Bank at the Dalal Jamm Hospital. Professor Sall's main area of research is onco-haematology, especially lymphomas and lymphoproliferative disorders, and, in particular, microRNA expression and IgVH gene mutation in chronic lymphocytic leukemia. Since 2013, she has been involved in developing flow cytometry for the diagnosis of leukemia and lymphomas in Senegal.

Dr Fatou Bintou Diagne, MD, is a paediatric oncologist at the Aristide Le Dantec University Hospital, Cheikh Anta Diop University, Dakar, Senegal. She has been working in paediatric oncology since 2007. She graduated from DIUOP, University Hospitals Paris-Sud, in 2014 and is interested in paediatric lymphoma and improving early diagnosis and cure rates.

Doctor Fatimata Bintou Sall, MD, is a haematologist at the Aristide Le Dantec University Hospital, Cheikh Anta Diop University, Dakar, Senegal. She is a PhD student since 2017 at CNRS-UMR9018-Gustave Roussy Institute (Paris-Saclay University) and the Hematology Laboratory at Aristide Le Dantec Hospital (Cheikh Anta Diop University). Her research interests are in the onco-haematology field, mainly lymphomas and in particular the mechanisms of lymphomagenesis related to Epstein-Barr and human immunodeficiency viruses.

Professor Aurore Coulomb, MD, PhD, is a paediatric pathologist and Head of the Pathology Department at Armand Trousseau/La Roche Guyon University Hospital, AP-HP, Sorbonne University, Paris, France. An MD since 1993 and PhD since 2000, with 25 years' experience in paediatric pathology, her main interest is in paediatric oncology. She has been Professor of Pathology since 2007 and involved in research focusing on renal tumors in children. She is a member of PPS (Paediatric Pathology Society) and IPPA (International Paediatric Pathology Association), SFCE (Société

Française des Cancers de l'enfant), RTSG (Renal Tumor Study Group), SIOP (Société Internationale d'Oncologie Pédiatrique), and the AMCC (Alliance Mondiale Contre le Cancer).

Doctor Elisabeth Auberger, MD, is a pathologist at the Simone Veil Hospital, Eaubonne, France. She specializes in pathology, cytology and foetopathology, and is a hospital practitioner as Head of the Pathology Department at the Simone Veil Hospital. As coordinator for training programmes for pathologists in sub-Saharan Africa, she has led missions in several hospitals in Madagascar, Ivory Coast and Mali for the French African Group for Paediatric Oncology (GFAOP). She is a member of the Board of the Alliance Mondiale Contre le Cancer (AMCC), and is closely involved in telepathology via the telemedicine network i-Path and in e-learning for the African School of Paediatric Oncology EAOP.

Dr François Desbrandes is Head of the "My Child Matters" childhood cancer programme at the Sanofi Espoir Foundation in Paris, France. He has 30 years of experience in the pharmaceutical industry in low- middle- income countries, holding several positions in Sanofi, including Head of Industrial Development in the Asia Pacific, based in Ho Chi Minh City (Vietnam), and General Manager in West Africa, based in Dakar (Senegal). He developed Sanofi's Access to Medicines Operations and the Malaria programme for 10 years and served as the private sector representative on the Regional Steering Committee for the Mekong Malaria Elimination Initiative (RAI2E). After a CSR position as Head of Access to Healthcare for the Underserved, he joined the Sanofi Espoir Foundation as Head of the paediatric oncology "My Child Matters" programme.

References

1. WHO Global Initiative for Childhood Cancer WHO; 2018. Available from: <https://www.who.int/cancer/childhood-cancer/en/>
2. Howard SC, Zaidi A, Cao X, Weil O, Bey P, Patte C, et al. The My Child matters program: effect of public-private partnerships on pediatric cancer care in low-middle-income countries. *Lancet Oncology* 2018; 19 (5): 252-66
3. Brauchli K, O'mahony D, Banach L, Oberholzer M. iPath – a Telemedicine platform to support health providers in low resource settings. *Stud Health Technol Inform* 2005; 114:11-7
4. Raphaël M, Hurwitz N. Support diagnostique en cancérologie : techniques complémentaires et apport de la télépathologie, exemple de l'hématopathologie. *J Afri Cancer* 2011; 3: 213-14
5. Raphaël M, Auberger E. Diagnosis support with telepathology. I-Path telemedicine platform, present and future. Congrès AMCC/INCTR SAFHEMA. *Lymphoma*. What can we learn from Africa. Dakar, November 12-14, 2015.
6. Ilunga J, Raphaël M. Telepathology: Role in improving laboratory techniques, diagnosis and research in low resource countries. Katanga, LCCC-UNILU, Lubumbashi. The Democratic Republic of Congo Paris, AMCC. World Cancer Congress, Paris, October 31 -November 3, 2016.
7. Raphaël M. Second opinion in Hematopathology. The experience of Francophone Africa using telepathology. World Cancer Congress, Paris, October 31 -November 3, 2016.
8. Auberger E, Lebwaize B, Traore C, I. Abbès I, Dial C, Randrianjafisamindrakotroka NS, Kouï S, Doukoure B, Nkegoum B, Hurwitz N, Raphaël M, Coulomb A. Impact of second opinion using telepathology to support diagnosis in pediatric oncology in Africa. SIOP, Lyon, October 23-26, 2019.
9. Hurwitz N, Ticheli A, Tzankow A, Raphael M, Auberger E, Coulomb A. The "INTRCommunity on iPath", a software for professional dialogue Francophone and Anglophone division. Coordinators: Francophone division: M. Raphael, Anglophone division: N. Hurwitz. The "Swiss Venture Forum", Afrilab Annual Gathering Meeting. Addis Ababa, Ethiopia, October 28-30, 2019.
10. Naresk K, Raphaël M, Ayers L, Hurwitz N, Calbi V, Rogena E, Sayed S, Sherman O, Hibrain H, Moumouras V, Rince P, Githanga J, Byakika B, Moshi E, Durosimi M, Olasode B, Oluwasola A, Akang E, Akenova Y, Adde M, Magrath I, Leoncini L. Lymphomas in sub-Saharan Africa – What can we learn and how can we help in improving diagnosis, managing patients and fostering translational research. *Brit J Haematol* 2011; 154, 696-703
11. Naresh K, Ibrahim HAH, Lazzi S, Rince P, Onorati M, Ambrosio MR, Bilhou-Nabera C, Furrat A, Reid A, Mawanda M, Calbi V, Ogwang M, Rogena E, Byalila B, Sayed S, Moshi E, Mwakigonja A, Raphaël M, Magrath I, Leoncini L. Diagnosis of Burkitt lymphoma using an algorithm approach applicable in both resource-poor and resource-rich countries. *Brit J Haematol* 2011; 154: 770-76
12. Amato T, Sall A, Ndiaye Dièye T, Gozzetti A, et al. Preferential usage of specific immunoglobulin heavy chain variable region genes with unmutated profile and advanced stage at presentation are common features in patients with chronic lymphocytic leukemia from Senegal. *Am J Clin Pathol* 2017; 148(6):545-54

Understanding breast cancer survivorship in Tanzania

Dr Nazima J Dharsee (left), Ocean Road Cancer Institute, Dar es Salaam, Tanzania and **Professor Theresa Wiseman** (right), The Royal Marsden NHS Foundation Trust, University of Southampton



Survivorship in cancer is a relatively new concept in the developing world. Traditionally, the focus of cancer care in this region has been on early identification of cases, provision of curative treatment where possible, and palliative care for the symptoms of advanced disease. However, with an increasing number of patients who are now “survivors”, living with and having completed cancer treatment, there is a growing need to understand and address the unique challenges faced by this group.

According to the National Cancer Institute’s Office of Cancer Survivorship, an individual is considered a cancer survivor from the time of diagnosis through the balance of his or her life (1). There are a growing number of individuals living with and after cancer globally – an estimated 43.8 million living within a 5-year diagnosis of cancer as per IARC’s report on Global Cancer Data 2018 (2). Survivorship care requires dealing with a number of different elements in cancer care that may not be typically addressed by standard hospital-based cancer services, including the physical, psychosocial, and economic issues of cancer, beyond the diagnosis and treatment phases, the ability to get healthcare and follow-up treatment, late effects of treatment, second cancers and quality of life. It also actively involves family members, friends and caregivers (3–5).

The need for survivorship care in Tanzania

Tanzania is a low-middle income country in East Africa, with a current population of 58.01 million. According to Globocan estimates, 42,080 new cancer cases occurred in 2018, resulting in 26,810 deaths; and over 75,000 prevalent cases existed over a 5-year period in the country. Most cancer cases are treated at the Ocean Road Cancer Institute (ORCI), Tanzania’s national cancer referral centre that provides chemotherapy, radiation therapy, and palliative care, and also serves as a training centre.

Breast cancer (BC) is the second most common cancer among women in Tanzania and accounted for nearly 13% of the 7,650 new cases seen at ORCI in 2018. The majority of patients present with late stage disease, many of them seeking healthcare when they experience pain, skin ulceration or other advanced symptoms (6–8). Typically, patients have undergone surgery (most commonly mastectomy) when they arrive at ORCI for adjuvant therapy; a significant number also present with metastatic disease.

Knowledge about BC varies significantly among women.

Women may be aware about BC but less informed about its symptoms and risk factors; myths surrounding the disease are common and screening for BC is rare (9). Many women are stigmatized and socially isolated after receiving mastectomy. BC in African patients has also been documented in several studies to affect younger women and present in a more aggressive form than that in western countries (10). With only a few centres in the country providing chemotherapy and radiotherapy, patients often have to travel great distances and remain away from their families to access these services. The lengthy treatment involving chemotherapy and radiotherapy for these patients and the impact of distance from family mean that many patients are likely to experience significant physical, emotional and social consequences of the disease and its treatment.

With the increasing number of BC patients living as “survivors” in Tanzania, it was important to understand the needs of this special population and look into ways of providing resources and services where these needs were not being addressed. This article will discuss some of the initiatives instituted at ORCI to address this area.

The ORCI breast cancer patient support group

This group was established in June 2017 and aimed at providing support to BC survivors and patients currently on treatment at ORCI. The main activity of the group is a monthly meeting currently attended by 40–50 participants. Agendas include self-introductions, health talks given by local or visiting experts (topics range from dealing with side effects of treatment, nutrition, exercise, social support) followed by a question and answer session and a sharing of experiences. The support group often works in collaboration with other local services such as the Tanzania Breast Cancer Foundation and The Aga Khan Hospital. A collaboration with a local volunteer group “Knitters without Borders” has allowed post-mastectomy patients to get free access to crocheted hand-made breast

prostheses (modeled after the “Knitted Knockers” design) through a monthly fitting and distribution scheme supported by the group (11).

The patient support group has become a well-established and popular meeting place for BC survivors, evidenced by the increasing numbers of participants. It is considered a safe and comfortable forum for patients to exchange experiences and provides an excellent opportunity to educate patients, provide peer support and partner with donors and supporters from the community. Facilitating the sharing of experiences and responding to the questions by participants has provided a window of understanding into the informational needs of these patients, which formed the background of a new project to address this gap – the resource centre for patients with metastatic breast cancer.

The Holistic Needs Assessment (HNA) project

This project, which was funded by the Institute of Cancer Research’s Global Challenges Research Fund (ICR–GCRF), was aimed at exploring the feasibility of implementing the “Recovery Package” (including the holistic needs assessment (HNA), care plan and treatment summary) for patients after primary BC treatment in two African centres (Tanzania and Ghana) (12). The primary objective of the project was to define the unmet needs of women with BC in these centres using the HNA tool and compare this with data from the United Kingdom (already available and published) (13), while the secondary objective was to investigate the real challenges faced by women in these two geographical areas following diagnosis and treatment for BC.

A mixed methods approach was used that included participant observation, focus group discussions with patients, holistic needs assessment and provision of a care plan and/or treatment summary as needed. The Royal Marsden NHS Foundation Trust and the Royal Marsden/Institute of Cancer NIHR Biomedical Research Centre provided support with the research infrastructure. In order to implement this project, the available HNA tool was adapted to meet local cultural needs and translated into the local language. Members of the project team in both centres were trained in conducting HNAs and writing care plans and treatment summaries. Additional training sessions on the principles of qualitative research and mixed methods research, conducting focus group discussions and communication skills were organized. Participants were also trained on gathering and inputting data in a macro-database for statistical analysis.

The results of the participant observation and the focus group discussions with BC survivors highlighted a number of important themes; the lack of resources and facilities, the impact of cultural beliefs and practices in provision and

accessing care, and the important position of the nurse as a navigator in supporting access to cancer services. The role of peer support and sisterhood in resource-challenged environments was also brought to light, as was the importance of the support groups and meetings; the important role media played in the local context of cancer care was also highlighted.

The HNA project generated a dataset of the assessment of needs of 500 women who had undergone surgery for primary BC, and these were analyzed and compared with existing data from the UK dataset. It was realized that there were significant differences in reporting of symptoms and needs between the two African centres, with women in Ghana more likely to report on unmet needs than in Tanzania. There was also a variable use of care plans, and treatment summaries were not deemed important or necessary since a “primary physician model” (for whom the summaries would have been useful) did not exist in these environments, and most women returned to their cancer care centres for their follow-up needs. The results of the HNA project are due to be published soon.

Nurses training project – The foundations of cancer care

Nurses who participated in the training for the HNA project had expressed an eagerness for focused education in the foundations of cancer care, since many of them had very little specialized training in oncology nursing. A phase 2 project, also funded by the ICR–GCRF was initiated to meet this need. A focused group discussion with the team was held to analyze their learning needs, and a scoping review of literature, e-learning websites and hospice websites was conducted to access currently existing training resources that could be incorporated into the training.

A “Train the Trainer” model was chosen in order to empower participants with adequate resources and skills to allow them to continue training other nurses. The team developed a toolkit (including slides, content and exercises) addressing many of the basic issues in cancer care. Sessions on palliative and end of life care were prepared based on the contents of the World Hospice and Palliative Care Association’s Palliative Care Toolkit (14).

A 5-day teaching schedule was organized with classroom-based teaching in the mornings and patients-based/bedside teaching in the afternoons. Participants were instructed on how to teach and given opportunities at presentations to build their confidence in teaching the content of the course to others. A pre- and post-training confidence assessment was conducted; the evaluation showed a significant increase in the confidence and knowledge of nurses who completed the training in their understanding of basic cancer care and palliative care, and most participants expressed eagerness to continue teaching

this content to other nurses at the institute.

Resource centre for patients with metastatic breast cancer

ORCI was among the privileged recipients of the SPARC award offered by the Union for International Cancer Control (UICC) jointly with Pfizer Oncology in the year 2019 (15). This award, termed the SPARC (Seeding Progress and Resources for the Cancer Community) is a global grant aimed at supporting new ideas and projects specifically for patients with metastatic breast cancer (MBC). The awarded project plans to establish a resource centre to provide culturally sensitive and relevant information and support to MBC patients. It plans to do this through exploring gaps in the informational needs of women with MBC, developing appropriate patient educational materials, establishing a dedicated office space equipped with necessary tools, training nurses to man the resource centre and establishing a telephone helpline. It is expected that the project will result in development of a culturally acceptable and relevant repository of information accessible to patients with MBC, trained “champions” to disseminate this information, increased awareness about MBC to public and increased recruitment of women to the breast cancer screening clinic.

Lessons learned

As is the case with other LMICs, Tanzania faces significant challenges in terms of resources and manpower in providing oncology services across the entire spectrum of care, from diagnosis and early detection to palliative care. Establishing and sustaining services for survivors of cancer in these environments can be extremely difficult due to the competing needs of different groups of patients. In such circumstances, collaborations and partnerships with local and international partners can be a lifeline. A significant amount of work has already been done in understanding the needs of this group of patients and establishing services to meet them elsewhere, and much of this can be directly relevant to local settings.

It is however important to continue to work within the context of the individual healthcare set-up, and to recognize the unique cultural differences in needs between populations that may seem similar in other ways – a finding that has been highlighted through the holistic needs assessment project. Integrating survivorship services within existing health systems allows a more equitable use of scant resources, and increases the chances that they will become accepted and sustainable in the long run.

Peer support is crucial, both within patients and within healthcare workers, and should be actively supported. And while the needs of survivors are many, smaller initiatives that are easier to begin and sustain can together have a great impact on the quality of life of these patients. ■

Professor Theresa Wiseman is a clinical nurse academic with a joint appointment between The Royal Marsden NHS Foundation Trust and the University of Southampton. She holds a chair in Applied Health Research in Cancer Care, is passionate about research that makes a difference to patients and families. She is the Executive Board Secretary of the European Oncology Nursing Society (EONS), Executive Board Member of the European Cancer Organisation (ECO), Executive Board Member of ABC Global Alliance and Executive Board Member of Breast Cancer International. Theresa’s research focuses on the patient experience of cancer and treatment and developing services and interventions to ameliorate that experience. Current work involves digital technology (Supportive Care Apps and Virtual Reality) to enhance coping with cancer treatment. Her international work involves developing research capacity and survivorship pathways in Ghana and Tanzania.

Nazima Dharsee, MD, MMed, MSc, is Director for Academics, Research and Consultancy at the Ocean Road Cancer Institute in Dar es Salaam, Tanzania. She oversees training activities at the Institute and coordinates research projects within and in collaboration with partner institutions.

References

1. Statistics, Graphs and Definitions - Office of Cancer Survivorship [Internet]. [cited 2020 Mar 23]. Available from: <https://cancercontrol.cancer.gov/ocs/statistics/index.html#definition-survivorship>
2. PRESS RELEASE N° 263 [Internet]. 2018 [cited 2020 Mar 24]. Available from: <http://gco.iarc.fr/>,
3. Denlinger CS, Carlson RW, Are M, Baker KS, Davis E, Edge SB, et al. Survivorship: Introduction and definition: Clinical practice guidelines in oncology. *JNCCN Journal of the National Comprehensive Cancer Network*. 2014 Jan 1;12(1):34–45.
4. McCabe MS, Bhatia S, Oeffinger KC, Reaman GH, Tyne C, Wollins DS, et al. American society of clinical oncology statement: Achieving high-quality cancer survivorship care. *Journal of Clinical Oncology*. 2013 Feb 10;31(5):631–40.
5. Definition of survivorship - NCI Dictionary of Cancer Terms - National Cancer Institute [Internet]. [cited 2020 Mar 24]. Available from: <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/survivorship>
6. Ashley M, Burson & Amr S, Soliman. Clinical and Epidemiological Profile of Breast Cancer in Tanzania. *Breast Dis*. 2014;31(1):33–41.
7. Mansouri H, Mnango LF, Magorosa EP, Sauli E, Mpolya EA. Ki-67, p53 and BCL-2 Expressions and their Association with Clinical Histopathology of Breast Cancer among Women in Tanzania. *Scientific Reports*. 2019 Dec 1;9(1):1–11.
8. Rambau P, Chalya P, Manyama M, Jackson K. Pathological features of Breast Cancer seen in Northwestern Tanzania: A nine years retrospective study. *BMC Research Notes* [Internet]. 2011 Dec 22 [cited 2020 Mar 24];4(1):214. Available from: <https://bmcresnotes.biomedcentral.com/articles/10.1186/1756-0500-4-214>
9. Morse EP, Maegga B, Joseph G, Miesfeldt S. Breast cancer knowledge, beliefs, and screening practices among women seeking care at district hospitals in Dar es Salaam, Tanzania. *Breast Cancer: Basic and Clinical Research*. 2014;8(1):73–9.
10. Kantelhardt EJ, Frie KG. How advanced is breast cancer in Africa? Vol. 4, *The Lancet Global Health*. Elsevier Ltd; 2016. p. e875–6.
11. Knitted Knockers | Knitted Knockers Organization | Knit Prosthetics for Breast Cancer Survivors | Barbara Demorest [Internet]. [cited 2020 Mar 24]. Available from: <https://www.knittedknockers.org/>
12. Recovery Package | Holistic Needs Assessment - Macmillan Cancer Support [Internet]. [cited 2020 Mar 26]. Available from: <https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/recovery-package>
13. Capelan M, Matteo Luca Battisti N, McLoughlin A, Maidens V, Snuggs N, Slyk P, et al. The prevalence of unmet needs in 625 women living beyond a diagnosis of early breast cancer. 2017 [cited 2020 Mar 26];117. Available from: www.bjcancer.com
14. Lavy V, Bond C, Wooldridge R. Palliative Care Toolkit Improving care from the roots up in resource-limited settings [Internet]. 2008 [cited 2020 Mar 26]. Available from: www.palliativecareworks.org
15. 11 cancer organisations selected for the 3rd round of the SPARC MBC Challenge | UICC [Internet]. [cited 2020 Mar 24]. Available from: <https://www.uicc.org/news/11-cancer-organisations-selected-3rd-round-sparc-mbc-challenge>

Cancer control in sub-Saharan Africa and its impact on health systems strengthening: A case study from Ghana

Dr Beatrice Wiafe Addai, Chief Executive Officer and Senior Medical Officer,
Peace and Love Hospitals in Accra and Kumasi, Ghana



By adopting the principles of primary healthcare and by working in conjunction with the non-governmental organization (NGO) Breast Cancer International, the Peace and Love Hospital (PLH) at Kumasi, Ghana, has empowered its local community by raising the levels of awareness about breast cancer in the population. As a result, over the past five years more than a quarter of a million people have been reached, self-referrals have increased and 141,729 women have been screened. This successful synergy between an NGO and a private health institution (PLH) draws attention to the important role that NGOs and civil society organizations can play.

The rate at which the overall disease burden in sub-Saharan Africa, attributable to cancer, is rising is alarming. Sub-Saharan Africa is predicted to have a 85% increase or more in the cancer burden by 2030 (1). Strategies to minimize the burden of cancer in sub-Saharan Africa in the past few years have had little or no impact because of the following factors:

- ➔ low awareness of the cancer burden on the part of decision makers;
- ➔ a poor understanding of the potential for cancer prevention;
- ➔ myths and misconceptions due to lack of awareness among communities;
- ➔ unsatisfactory management by health professionals due to lack of training and poor exposure to technical and soft skills;
- ➔ late presentation by patients which may not be due to their fault or negligence but due to delays within facilities when it comes to management of cancers;
- ➔ poorly equipped health facilities;
- ➔ affordability – costs (direct and indirect);
- ➔ distance – all cancer treatment facilities are based in the big cities;
- ➔ poverty – the absence of social support systems for people diagnosed with cancer.

Breast cancer is known as the most commonly diagnosed cancer in women and also the principal cause of death from cancer among older women, but it has lately been diagnosed

more often in the younger age groups. In Ghana, breast cancer is considered the leading cause of death among women, accounting for 15% of all malignancies. According to the most recent GLOBOCAN report, Ghana recorded 4,645 (20.4%) new breast cancer cases in 2018. It is estimated that the majority of breast cancer patients are women between the ages of 35–50 years, which is younger than Caucasian women in America who are often diagnosed at around 60 years of age.

Comprehensive cancer control has to be started with education and awareness creation.

Late stage presentation of all cancers in sub-Saharan Africa account for the high mortality rates. Hence all efforts should be geared towards early detection, early diagnosis and early treatment.

Case study: The Peace and Love Hospital/Breast Care International model, Kumasi, Ghana

Breast Care International (BCI) is Africa's leading breast cancer awareness charity, delivering educational programmes survivor support as well as research and breast cancer screening programmes throughout Africa (Figure 1). Its mission is to bring hope, health and empowerment to communities in Ghana through the provision and dissemination of quality breast health education, screening, counselling, advocacy, research, treatment and support to intensify breast cancer awareness and improve the quality of life of women at risk of breast cancer. BCI's vision is to maximize personal and community wellness through community participation, excellence in public health education and practice, and empowering people to save

lives and end late-stage breast cancer presentation in Ghana. The ultimate goal of BCI is to reduce the number of women who show up and are diagnosed with late-stage diseases through community outreach and education.

The Peace and Love Hospital, the subject of this case study, is a specialist hospital and is located in the Ashanti Region. There are 43 districts in the Ashanti Region; the remainder of the area served lies in Bono, Bono East, Ahafo, Western North, Central and Eastern regions bringing the catchment population to approximately 7 million.

The collaboration between Breast Care International and the Peace and Love Hospital in Kumasi provides a good example of what can be achieved for cancer care in low- and middle-income countries (LMICs) with slender resources. Peace and Love demonstrates well how community cancer care works, both in the way the service is structured and in its achievements.

The Peace and Love Hospital is a specialist hospital with a strong emphasis on breast pathology. Established in 2002, the hospital is staffed by the following categories of staff: physicians, surgeons, nephrologists, a urologist, radiologists, obstetricians and gynecologists, pharmacists, nurses, laboratory technologists and technicians, researchers, counsellors and administrative staff.

One distinguishing characteristic is the presence of a strong Public Health Department that looks after the public health aspects of breast pathology – Breast Care International. The role this department has played is a contributing factor to the success of this programme, which has created demand for the hospital's cancer services by:

- ➔ increasing breast cancer awareness and education in communities;
- ➔ educating women about the risk factors of breast cancer, prevention strategies, and availability of various treatment options;
- ➔ providing voluntary clinical breast examination (CBE) to women in their catchment areas;
- ➔ teaching women to perform their own breast examinations with demonstrations;
- ➔ aiding and directing those patients found with suspicious lesions to go to treatment centres.

Figure 1: BCI/PLH Breast healthcare management model

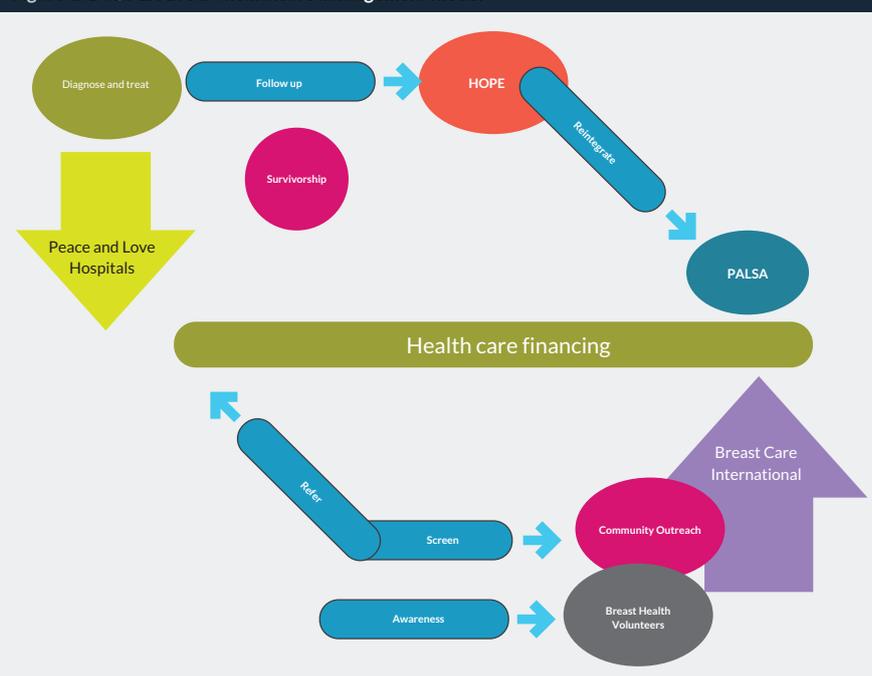


Table 1: BCI/ Peace and Love Hospital model: Increases in population breast cancer awareness and screening 2015–2019

Activity/Year	2015	2016	2017	2018	2019	Total
Number reached through awareness creation	38,955	45,210	47,946	53,299	73,309	258,719
Number screened	12,250	15,450	19,708	37,208	57,113	141,729
Number referred for treatment	935	1,850	1,098	574	465	4,922

Through this model there has been a manifold increase in the awareness levels of the population about breast cancer. Over the past five years we have educated over a quarter of a million people and, as a result, self-referrals have increased and we have screened 141,729 women (See Table 1).

How has this happened?

The Peace and Love Hospital applied the primary healthcare principles in their approach and in offering services as close to the communities as possible. We empowered communities to be able to identify the problems early. When this is done, they know where to go and are willing to accept treatment.

Counselling services are readily available through all the initiatives that have been carefully developed, using peer counselling strategies and volunteers.

Throughout this process, the referral system is strengthened so that late presentation is minimized. When patients are managed close to their communities, travel distance is kept down and therefore the financial burden is also reduced.

Through this model no one is ever turned away because he or she is too poor to pay. The programme has the less-well

off in mind and has built a safety net. Well-wishers make donations to help fund those who cannot pay.

In summary the strategy includes the following:

- ➔ A strong community approach to cancer care to augment national and individual endeavours.
- ➔ A greatly improved distribution of specialist human resource teams.
- ➔ A greatly improved availability of specialist care even at the community level.
- ➔ A greater availability of referral centres and centres to develop the cancer programmes.
- ➔ Financing of the care of the cancer patients.

Health system strengthening

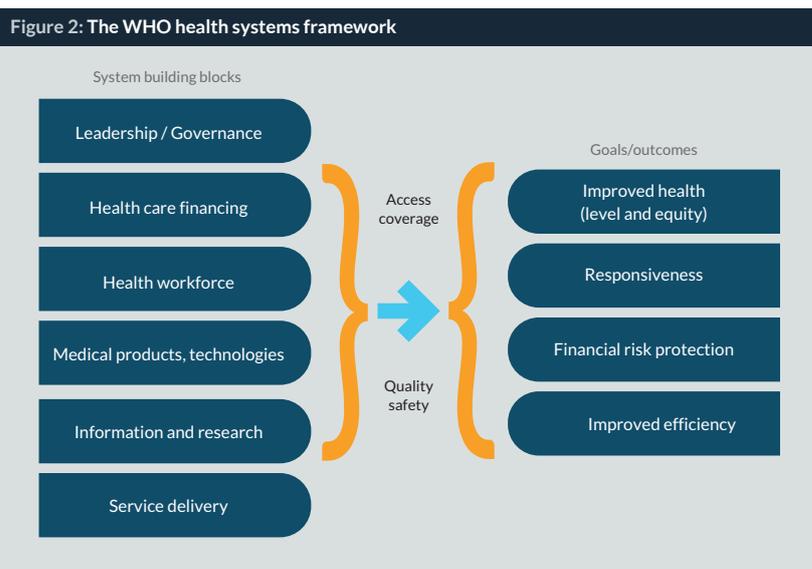
This type of approach addresses each one of the six building blocks set up by the World Health Organization (WHO) under its health system strengthening agenda. This includes the following six building blocks:

1. **Leadership and governance** involve ensuring the existence of policy frameworks combined with effective oversight, coalition building, regulation, attention to system design and accountability.
2. **A good health financing system** raises adequate funds for health, in ways that ensure people can use needed services and are protected from financial catastrophe or impoverishment associated with having to pay for them.
3. **A well-performing health workforce** is one that works in responsive ways, fairly and efficiently, to achieve the best health outcomes possible, given available resources and circumstances
4. **A well-functioning health system** ensures equitable access to essential medical products, vaccines and technologies of assured quality, safety, efficacy and cost-effectiveness, with scientifically sound and cost-effective use.
5. **An information system** is one that ensures the production, analysis, dissemination and use of reliable and timely information on health determinants, health system performance and health status.
6. **Good service deliveries** are those which deliver effective, safe, quality personal and non-personal health interventions

References

1. Morhason-Bello, IA et al. Challenges and opportunities in cancer control in Africa; *Lancet Oncol* 2013;14:e142-51.
2. World Health Organization (WHO). Everybody's business- strengthening health systems to improve health outcomes: WHO's framework for action. WHO; Geneva:2007. http://www.who.int/healthsystems/strategy/everybody's_business.pdf

3. World Health Organization (WHO). Monitoring the building blocks of health systems: a handbook of indicators and their measurement strategies. Geneva, Switzerland: WHO; 2010.



to those that need them, when and where needed, with minimum waste of resources.

WHO has supported its health system framework with a monitoring and evaluation framework to monitor programme management of health system investments, assess health system performance and evaluate the results of health reform investments (3).

Conclusion

The collaboration between BCI and the Peace and Love Hospital demonstrates well how community cancer care works, both in the way the service is structured and in its achievements. It provides a fine example of what can be achieved for cancer care in LMICs with minimal resources. This is true for the care the hospital provides within its own Ashanti Region and beyond in its broader area of outreach.

The successful synergy between a non-governmental organization (BCI) and a private health institution (Peace and Love Hospital) draws attention to the important role that NGOs/CSOs can play, and is worth emulating. Working in harmony with BCI, the Peace and Love Hospital is able to achieve success and, by extension, other hospitals can do the same. ■

Dr Beatrice Wiafe Addai has over 30 years experience as a medical officer in Ghana. She is the Chief Executive Officer and the Senior Medical Officer of the Peace and Love Hospitals in Accra and Kumasi; President, Breast Care International (BCI), Ghana; Vice President of AORTIC, West Africa and Chairperson of the Ghana Breast Cancer Alliance.

Diagnostic imaging challenges to the poor on the long road to the cancer centre

Dr Elizabeth Joekes (left), Co-founding Director, Worldwide Radiology and Consultant Radiologist, Liverpool University Hospitals Foundation Trust, UK; and **Dr Sam Kampondeni** (right), Neuroradiologist, Queen Elizabeth Central Hospital, Blantyre, Malawi



Imaging is one of the key pillars on which cancer detection and treatment rely. Yet the poor who constitute the majority of patients in emerging health systems face great barriers to access. Centres with specialist imaging facilities are out of reach. Local facilities are neglected. New generations of X-ray and ultrasound equipment, in combination with digital connectivity are an exciting opportunity for the imaging community and health providers to close this gap. Resource-stratified guidelines, an “essential radiology package” and a new look at imaging work force development are some of the proposed solutions discussed in this article.

Cancer patients in low- and middle-income settings face a host of challenges, including lack of awareness, long delays between onset of symptoms and diagnosis, poor access to treatment, catastrophic health expenditure and lack of access to palliative care. Global cancer care initiatives target these challenges with a range of interventions, from raising awareness in the community to advocating investment in the presence of at least one specialist cancer centre in each country (1).

In high-resource settings, state-of-the-art diagnostic imaging, or radiology, is considered indispensable for the detection, staging and monitoring of the large majority of cancers. High-end imaging modalities, such as Computed Tomography (CT), Magnetic Resonance Imaging (MRI) and nuclear medicine are commonplace, along with interventional radiology treatment options. Over the last two decades, specialist cancer centres and tertiary level hospitals in low- and middle-income settings are increasingly being equipped with these modalities, prompting similar state-of-the-art access to cancer diagnosis and treatment. However, as these modalities require major financial and human resource investment, roll-out on a wider scale is not feasible in many current healthcare systems. Therefore, they will remain inaccessible to a large proportion of poorer populations.

Increasing awareness and early detection are important drivers to improve cancer outcomes. However, many patients in low- and middle-income settings are geographically removed from the major treatment centres and will rely on local and secondary services to manage their disease after early detection. Some resort to alternative therapies, including herbal

medicine and spiritual healing. The majority cannot afford the high cost of imaging tests even if they existed in the vicinity, and an estimated 80% of patients currently present with advanced disease in which case it is unlikely that they will benefit from a journey to a specialist centre. Palliative radiotherapy being the only exception for those who can afford it. The challenges these patients face include not only those above, but also a lack of access to high quality, more affordable diagnostic imaging tests closer to home. This particular challenge is rarely highlighted, yet acknowledging and addressing it may play an important role in distinguishing, at the local level, between patients who are most likely to benefit from referral for more complex management and those who are best cared for at their local or regional level. For patients needing referral, but lacking financing, basic imaging can provide useful information for optimizing local care. In this context it is worth highlighting that, from prior experience in tuberculosis programmes, it is a known fact that many patients will not be able to afford even what are considered to be simpler tests such as chest X-rays (2).

To illustrate the problem, Figure 1 shows the view taken from

Figure 1: The long road to the cancer centre – the view from a rural clinic in Malawi (Credit: Personal collection, E Joekes)



a rural clinic in Malawi. It is situated along the highway between two large, urban centres. The nearest CT scanner in the public system is 300 km to the north. The nearest functioning MRI and ultrasound service are 200 km in the opposite direction. The nearest X-ray, in the local district hospital, no longer works, whilst the nearest ultrasound machine is collecting dust in a spare room of the clinic. The medical officer who runs the clinic is unable to use it. Therefore, not only patients with symptoms of possible cancer, but all patients have to travel long distances for imaging tests. This scenario is unfortunately not uncommon.

This widespread shortage of functional basic equipment is paradoxically increasingly combined with a growth in high-end equipment at inappropriate levels of care. A severe global shortage of human resources in diagnostic imaging, including in high-resource countries and private centres means that expertise at all staffing levels is diverted to these larger, better equipped and often urban centres, leaving many lower-level facilities in the hands of technicians and clinicians, or abandoned (3, 4). This is a problem across many sectors in healthcare, but it is particularly acute in radiology.

Clinicians and technicians left to run the peripheral services are not imaging experts and may not be familiar with the potential of X-ray and ultrasound as useful modalities in the diagnosis and staging of cancer. They may also struggle to effectively advocate for the strengthening of these services. The implementation of these tests in low- and middle-income settings has traditionally been associated with communicable diseases, obstetrics and acute surgical care. With the increasing global prevalence of cancer, there is a need to expand the evidence base, knowledge and education on how these modalities can also be deployed effectively in the diagnosis, staging and management of cancer patients. This applies not only to healthcare professionals providing the imaging services at rural and district levels, but also to referring clinicians and policy makers, who may be more focused on the implementation of complex, high-end imaging and treatment modalities, so frequently quoted as essential to cancer care.

A further explanation for the underutilization and neglect of basic modalities is the fact that the training and practice of imaging professionals, both medical and technical, is primarily concentrated in centres where more complex imaging modalities are well established. Being shaped by the developed world, radiology and radiography curricula, equipment development, research and literature are heavily biased towards increasingly sophisticated techniques, with the dissemination of guidelines and equipment targeted to the maximum level of care available. X-ray and ultrasound are now viewed as triage tests before further complex imaging, rather than as the definitive test. While this is mostly appropriate in

well-resourced settings, it creates an unintentional bias in the recommendation of definitive imaging tests for patients who present to lower levels of care or who are too poor to access specialist care. This bias is also reflected in the World Health Organization (WHO) list of priority medical devices for cancer management (5). The document clearly emphasizes that services should be in line with local and national healthcare capacity and needs, yet relies almost entirely on cancer imaging guidelines derived from high- and high-middle-income settings, distorting priorities by affording the same importance to high-end facilities as well as basic facilities. A lack of awareness within the imaging community of existing resource-stratified guidelines for cancer may also contribute (6).

Using the Breast Global Health Initiative (BGHI) resource levels as an example, a maximum level of services is defined as those that are available in highly-resourced systems, applying cancer guidelines that do not take resource levels into consideration (7). Importantly, this maximum level of resources is considered of lower priority than the level required to develop the basic, limited or enhanced levels of care. Treatment and diagnostic capacity should be matched and the level of complexity of imaging tests in line with the overall level of care provided. The BGHI therefore recommends excluding any breast imaging from the basic level, developing ultrasound and/or mammography services for symptomatic patients at the limited level and population screening at the enhanced level. In a region where the lower levels have not been developed, there is little justification to spend a large proportion of the cancer imaging budget on the implementation and maintenance of a breast MRI service, despite MRI being included in the WHO list of essential equipment for cancer management. The budget required to implement one MRI service, including human resources and maintenance, will deliver many more high-quality breast ultrasound and mammography services at the limited level. If investment in MRI at the maximum level is considered appropriate, this will require simultaneous investment in the development of well-equipped and staffed X-ray, ultrasound and mammography services at the lower levels, in line with the breast cancer care pathway as a whole.

Resource-stratified guidelines such as those of the BGHI describe the whole spectrum of prevention, diagnosis and care for one specific type of cancer. Imaging recommendations form only a small part.

Given the overwhelming number of people with lack of access to higher level diagnostic imaging services, there is an urgent need to generate evidence on an expanded role for basic imaging modalities in cancer in low- and lower-middle-income settings, rather than relying on practice informed by high-income settings. Addressing questions such as how the most common types of cancers could be safely and effectively

triated closer to the community, according to which criteria and by whom; exploring the potential of task shifting and/or automated image interpretation; identifying optimal referral pathways and wider health system implications. This evidence will feed into the development of national or regional resource-stratified guidelines specific to imaging. These guidelines should afford the same importance to high-quality X-ray and ultrasound services at the limited level, as to the CT, MRI and nuclear medicine facilities at the maximum level. They should also reflect the reality that a large majority of patients present late and imaging may not be appropriate at all or should be as non-invasive as possible to avoid further harm and cost to the patient.

For example, if radiographers or clinicians at the limited level were given access to quality ultrasound equipment and the necessary knowledge and training to diagnose disseminated malignancies, this could be recommended as a first approach. Currently, referral for high-end tests, in the absence of such an explicit lower level solution, puts patients at risk of absconding and being lost to palliative care, or catastrophic financial outcomes. The high cost of tests such as CT, MRI and nuclear medicine means that this risk applies not only to those already in poverty, but also to many who are managing, but will end up below the poverty line as a consequence.

As an example, surgical treatment for a patient with suspected bowel cancer frequently depends on the presence or absence of spread of the cancer to the liver. At a time when improvement of surgical outcomes in low- and middle-income settings is considered a global priority, patients and their surgeons at limited and enhanced level centres should have timely access to a high-quality ultrasound service with an appropriately skilled operator to confirm or exclude spread to the liver. This will assist in triage and avoid unnecessary referrals, delay and costs. CT is evidently a more accurate test for the detection of spread to the liver, which is why it is recommended at the enhanced and maximum levels. However, in circumstances where CT is not available, implementing a quality ultrasound service is not only much more feasible and affordable, it also provides an invaluable addition to what would otherwise be a clinical assessment alone and possibly unnecessary major surgery. Asian resource-stratified guidelines for colon cancer take this into consideration by recommending ultrasound, rather than CT (6).

As always, resource-stratified cancer imaging guidelines are only one part of the solution and will mean little without major investment in the required infrastructure, human resource capacity and education. Put together they could form part of a new “essential radiology package”, similar to the “essential pathology package” (8). As mentioned above, a major added

benefit of this approach is the fact that high-quality imaging facilities at the limited level will also improve antenatal care and the management of many diseases other than cancer, for example, tuberculosis and other lung diseases, surgical emergencies and accidents, cardiovascular and neglected tropical diseases. It is estimated that functional basic imaging services are required to achieve 80% of the health goals of the 2030 Sustainable Development Goals (9).

Historically, X-ray equipment has been a challenge to implement sustainably in lower level facilities due to cost, complex infrastructure requirements, maintenance, and lack of skilled human resources. However, in the last decade, new digital solutions, including computer-aided diagnosis (CAD) and tele-radiology are contributing to overcoming these challenges; opening up opportunities to make X-rays available to a wider population and to link care and education at the limited level with experts at the higher levels. Combined with the development of light-weight mobile X-ray equipment and more robust and affordable fixed equipment, it is high time to revisit the idea that providing quality X-ray services at the limited or even community level is an insurmountable problem.

Similarly, ultrasound equipment has been revolutionized over the last two decades. Much is being written and advertized about low-cost, portable bedside scanners. While these clearly play a useful role in specific situations, they cannot replace the more sophisticated equipment needed for specialist use, such as in the example above. These higher-end machines now provide image quality that can rival with modalities such as CT and MRI, at a fraction of the cost and with none of the associated infrastructure and radiation safety concerns. This does not apply to all cases in cancer care, but it opens up the opportunity to start exploring the possibilities and benefits of implementing these techniques at the limited and even enhanced levels of care. Significant investment in skilled operators will have to be made, but the reach of their work will go well beyond cancer imaging alone. One proposed solution is to develop a new workforce with excellent skills in ultrasound and X-ray, as well as mammography and ultrasound guided biopsy, which could deliver the “essential radiology package”. A hub and spoke model would serve developing countries well, with peripheral centres sending cases/images to a central maximum level of care centre. This would bring equitable access to high-level care for all. ■

Liz Joekes would like to acknowledge her network of colleagues in several low- and middle-income countries mainly but not exclusively in sub-Saharan Africa, who have shared their challenges and thoughts over the years and informed much of the ideas expressed in this article.

Dr Elizabeth Joeke is a radiologist and Director of Worldwide Radiology. After an early career in interventional radiology and oncology, she moved to Ghana to become Head of Radiology at the Komfo Anokye Teaching Hospital, before taking up her current post in the United Kingdom, specializing in radiology in global health and infectious diseases. She is an Honorary Clinical Research Fellow at the Liverpool School of Tropical Medicine with an interest in implementation of computer-aided X-ray diagnosis in tuberculosis

and point-of-care ultrasound in resource-limited settings. She co-founded Worldwide Radiology with the aim of widening access to high-quality diagnostic imaging.

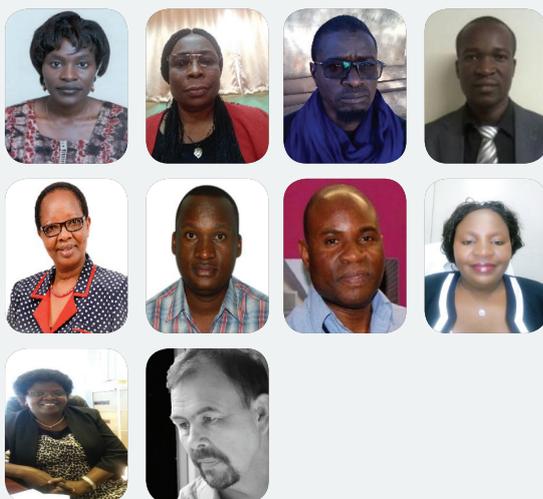
Dr Sam Kampondeni is a neuroradiologist practising in Blantyre, Malawi. He has interests in cerebral malaria research and the establishment of sustainable imaging services in developing countries that can be accessible to all.

References

1. 2017 WHA cancer resolution: From global commitment to national action. <https://www.uicc.org/news/2017-wha-cancer-resolution-global-commitment-national-action> UICC news. 2017.
2. Pedrazzoli D, Lalli M, Boccia D, Houben R, Kranzer K. Can tuberculosis patients in resource-constrained settings afford chest radiography? *Eur Respir J*. 2017;49(3).
3. Maboreke T, Banhwa J, Pitcher RD. An audit of licensed Zimbabwean radiology equipment resources as a measure of healthcare access and equity. *Pan Afr Med J*. 2019;34:60.
4. Tapera O, Dreyer G, Kadzatsa W, Nyakabau AM, Stray-Pedersen B, Sjh H. Health system constraints affecting treatment and care among women with cervical cancer in Harare, Zimbabwe. *BMC Health Serv Res*. 2019;19(1):829.
5. WHO. WHO list of priority medical devices for cancer management 2017 [Report]. Available from: https://www.who.int/medical_devices/publications/priority_med_dev_cancer_management/en/
6. Ku G, Tan IB, Yau T, Boku N, Laohavinij S, Cheng AL, et al. Management of colon cancer: resource-stratified guidelines from the Asian Oncology Summit 2012. *Lancet Oncol*. 2012;13(11):e470-81.
7. Yip CH, Anderson BO. The Breast Health Global Initiative: clinical practice guidelines for management of breast cancer in low- and middle-income countries. *Expert Rev Anticancer Ther*. 2007;7(8):1095-104.
8. Fleming KA, Naidoo M, Wilson M, Flanigan J, Horton S, Kuti M, et al. An Essential Pathology Package for Low- and Middle-Income Countries. *Am J Clin Pathol*. 2017;147(1):15-32.
9. The 2030 Sustainable Development Goals. <https://sustainabledevelopment.un.org/?menu=1300>. UC; 2015.

Using the African Digital Health Library for cancer control: Dissemination of African cancer research output

Christine Wamunyima Kanyengo (top left), Librarian, University of Zambia; **Dr Grace Ada Ajuwon** (top middle left), Principal Librarian, E Latunde Odeku Medical Library, College of Medicine, University of Ibadan, Nigeria; **Abdrahamane Anne** (top middle right), Medical Librarian, Faculty of Medicine, University of Bamako, Mali; **Muziringa Masimba** (top right), Health Librarian, formerly at University of Zimbabwe; **Nancy Kamau** (centre, left), University librarian, Kenya Methodist University, Kenya; **Justin Maranga Merande** (centre, middle left), Head of Electronic Resource Training, College of Health Sciences Library, University of Nairobi Library, Kenya; **Nason Bimbe, BSc, MSc** (centre, middle right), software developer; **Mercy Wamunyima Monde** (centre, right) Librarian, School of Medicine, University of Zambia; **Celine Maluma Mwafuilwa** (bottom left), Librarian, Medical Library, University of Zambia; **Mark Lodge** (bottom right), Executive Director, International Network for Cancer Treatment and Research UK; **Becky Lyon**; **Julia Royall**, Principal Investigator, African Digital Health Library



Access to published literature on cancer in Africa is problematic – especially locally produced cancer research information. A digital health library, such as the one being implemented in five African countries provides a solution. A new innovation, the African Digital Health Library draws support from local stakeholders, enlisting the best ideas from both the library and information technology fields. Although this work seems like new territory, it essentially remains a librarian’s workspace, supported by local collaborators and with new ideas to enable efficient access to cancer research information.

Evidence for cancer control principally comes from two sources: population-based cancer registries providing epidemiological data on cancer incidence, mortality and survival, and reports of research (basic, translational, clinical and economic) conducted in academic, clinical or commercial settings. In sub-Saharan Africa access to the former is improving with the support of the African Cancer Registry Network, but the latter remains problematic, with the lack of digitization making external access to valuable academic research particularly difficult. One project across five countries is trying to fill this gap by increasing access to locally published literature on cancer and by ensuring that it will be hosted in institutional repositories and made accessible globally.

Digital repositories are a recent phenomenon in African countries, and especially in universities. The traditional role of

a digital repository at a university in the United States is that of a storage place for faculty publications. These repositories are not usually accessible or user friendly as they are primarily used as warehouses of publications (1). Most African universities have embarked on establishing digital repositories with the objective of making their local content visible and permanently accessible to their users. They are an “increasingly significant component in the provision of academic publications and information resources” (2). These repositories are no longer just for storage, but are dynamic online spaces that clients may use for various purposes such as advocacy and marketing, ranking and as a general permanent archive. The digital health repositories in the five project countries of Mali, Kenya, Nigeria, Zambia and Zimbabwe were envisioned to be open, active and freely accessible to anyone with an internet connection.

The digital health repositories serve as vehicles for making African research, archival journal articles, dissertations and theses, as well as ministry of health reports, available to a global audience. For example, if African local research had been digitally accessible, responders and policy makers dealing with the 2014 Ebola outbreak in the three West African countries of Guinea, Liberia and Sierra Leone might have benefitted from being able to access reports from Uganda's outbreak in 2000 (1). It is common knowledge that a great deal of research has been carried out in Africa, by African academics. A substantial part of this research has been published as articles in international, regional and national peer-reviewed journals, while other research such as theses and dissertations are unpublished. Unfortunately, most of the published literature is not readily accessible by the institutions that produce it. The unpublished literature, such as dissertations and theses, are not accessible to a wider audience as they exist predominantly in print. Most of this research ends up on library shelves, where it is neither used to inform policy nor to generate further research. Although international funding has increased dramatically for biomedical scientists in Africa, there is little or no international access to the bulk of research that has been and is being carried out in the continent by African researchers. Importantly, this valuable information is generally not available to African researchers or their colleagues in the international community of global health and therefore does not inform current or future prevention, treatment, research and policy.

One of the ways of addressing this problem is to create Digital Institutional Repositories (DIRs). DIRs provide access to institutional research output by archiving it. They create global visibility for an institution's scholarly research and collect content in a single location, as well as storing and preserving other institutional digital assets, including unpublished (grey) or otherwise valuable information that could easily be lost.

A concerted action by a high-level network of African librarians in five countries has aimed to change that paradigm by creating institutional repositories that are searchable by anyone from any location worldwide. These DIRs aim facilitate

the dissemination of research output produced locally in the member countries of the Network of African Medical Librarians (NAML) as well as to the rest of the world. The ADHL project is implemented by NAML. It is locally led by medical librarians who, with the guidance of the principal investigators, have been collaborating and planning the project for several years. The Network comprises medical librarians from academic institutions in Kenya (Kenya Methodist University and University of Nairobi), Mali (Bamako University of Science and Technology), Nigeria (University of Ibadan), Zambia (University of Zambia) and Zimbabwe (University of Zimbabwe).

Country case studies

Accessing local cancer information in the five countries has been problematic. However, the ADHL project might be a solution to providing local cancer research to a wider audience; notably, facilitating access to this information by healthcare providers. The following case studies illustrate that within the short period that these repositories have been in existence, there is already cancer research that healthcare providers can reference in the delivery of healthcare.

Mali

Searching for "tumour" or "cancer" in the Mali Digital Health Repository database retrieves about 400 theses. The earliest documents related to liver cancer and stomach cancer surgery date back to 1981. These works that present the Malian context are not available in the published literature anywhere in the world. The digital copies have two origins: documents collected in electronic format from students (since 2002) and the documents digitized from hard copies the library had been collecting. The faculty has mandated the deposit of electronic copies. The older documents are being digitized when resources are available.

Zambia

The African Digital Health Library at the University of Zambia (3) has 232 items (of which 47 are cancer related) added from

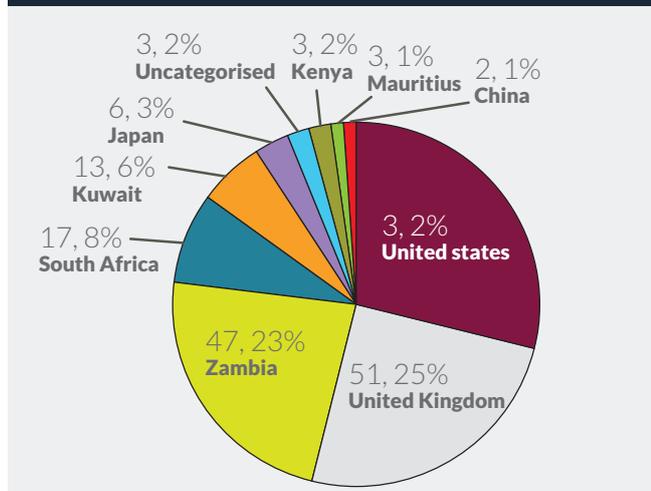
April 2018 to January 2019, and their combined full text downloads totalling 3,086 across all publications dates are shown in Table 1.

In terms of web traffic, we have seen the majority of access coming from the United States (59, 29%), United Kingdom (51, 25%), Zambia (47, 23%), South Africa (17, 8%), Kuwait (13, 6%), Japan (6, 3%), Kenya (3, 2%), Mauritius (3, 1%) and China (2, 1%). Three (2%) were not categorized. See Figure 1. There is also interest in the

Table 1: Breakdown by date of publication at UNZA ADHL

Publication date range	Total number of items	Total downloads	Average downloads
2010 - 2018	120	2,235	18.62
2000 - 2009	20	120	6
1980 - 1989	42	315	7.5
1970 - 1979	35	287	8.2
1967 - 1969	15	129	8.6
TOTALS	232	3,086	13.30

Figure 1: Views of research from the University of Zambia stored in the African Digital Health Library



content from within the country itself and from neighbouring countries, a phenomenon that can be observed from a digitization project of some African content (4) through a Department for International Development (DFID) funded Global Open Knowledge Hub project at the Institute of Development Studies in the United Kingdom (5).

However, as important as access to this African material is, the main outcome of this project was mentoring a group of seven librarians in five countries, their staff, their faculties, their information technology (IT) colleagues, and those they met with as they created the university-wide ecosystems required to hold the health repositories. The project output was working nascent repositories at each of the institutions, systems in place to support them, and training people to ensure their continuation. Repositories require systems and trained staff to support the entire process – from the scanning of the document to be deposited to the entry of documents into a database. Effective utilization of what is available requires people to make sure that the public are aware of the repository through training, marketing and advocacy. Consequently, vice-chancellors, provosts/deans, faculties, students, IT personnel and library staff are essential to this process.

Network of African Medical Librarians

NAML is an ongoing collaboration that has been working together since 2009 and comprises former United States National Library of Medicine Associate Fellows from Africa and affiliate librarians. The vision of NAML is to strengthen health sciences education, research and outreach for better health outcomes in Africa. The mission is to expand the frontiers of knowledge through training and outreach to African librarians, the academic community, healthcare professionals and health policy makers to source, organize and make use of this health information.

As a network, NAML has made significant advances, including the development of a training manual: *Finding, Organising, and Using Health Information*. The manual is available for free on the web at <https://library.adhl.africa/handle/123456789/2145> and has been used for conducting workshops for healthcare professionals at African universities and in outreach campaigns in the country. NAML has been active in improving access to research and healthcare information for researchers, students, healthcare workers and policy makers in Africa. The Network has also been involved in training students, health workers, academics/researchers and policy makers in member countries on accessing, retrieving and using online health information.

Funding for the project

The project is funded by the Office of the Global AIDS Coordinator (OGAC), the US Department of State, US National Library of Medicine and National Institutes of Health, and is managed by the US Civilian Research and Development Foundation (CRDF). The US National Library of Medicine has provided funding for high-grade scanners for the sites which did not have them. These scanners were purchased locally at each university.

Technology

The librarians collectively agreed on the Dspace software as the platform that was to be deployed across all repositories. This decision was partly based on the fact some of the countries were already using the software. Additionally, because Dspace is widely used on the African continent, availability of lessons from other Dspace users was much easier. There was also an agreement on metadata (data about data), which describe the content that was to be adopted. Dspace, an open source software, is a turnkey repository application used by many organizations and institutions around the world to provide access to digital resources. The librarians, working together as the NAML, identified the ecosystem that needs to be in place at each institution to support the Digital Health Repository (DHR).

Major activities for the IRs

Among the major activities undertaken were:

- ➔ Developing metadata standards to be used by all the Network Libraries.
- ➔ Identifying the appropriate software.
- ➔ Identifying technical expertise.
- ➔ Setting up an advisory sub-committee composed of key players.
- ➔ Developing criteria for the identification of contents.
- ➔ Scanning/digitizing the printed information to populate the IRs.
- ➔ Developing a federated search engine (ability to search

across the Network IRs).

- ➔ Training the librarians (administrators of the IRs) on use of IRs.
- ➔ Conducting training and advocacy workshops on open access and online publishing for the academic community and for authors and researchers on how to input and retrieve research evidence,
- ➔ Importance of on-site visits and training in the provincial nursing schools under the Ministry of Health in Zambia. The Zambia node has already embarked on this very important move of teaching health professionals how to easily access the resource to save lives.
- ➔ Marketing of the IRs within the institutions, nationally and internationally, while mentoring young professionals in their use and application.
- ➔ It is hoped that the provincial health professionals will in return inform their colleagues in the remotest health centres why this resource is useful to them.

Mentoring younger professionals

Mentoring is essential to building a strong DHR and for the ADHL, and this took place at all levels. Initially, the first phase comprised site visits by the project's principal investigators (PIs) who are based in the United States. They met physically or through conference calls with the individual librarians at each site. Together, they were to ensure that the policy makers, faculty, students, library staff, IT personnel and local ministries of health were all engaged, identify any gaps, and give assistance where needed. However, this approach was abandoned in favour of conference calls due to difficulties in coordinating site visits. The objective for the first phase of mentorship of the project at site visits was a narrative, budget, and timeline for each institution, created by the librarians with the help of the PIs. The budget for each site was based on the needs of each institution to support and sustain the digital health repository. This budget and narrative was then sent to CRDF shortly after the conclusion of each visit. The objective was for the librarians to be strengthened so that they can carry on with their own repositories as well as reach out to, and mentor, those within the network whose repositories might have been more nascent.

Content for the ADHL

Only local research content and outputs from NAML member countries was considered for the repository. The content included the following:

- ➔ journal articles published in open access journals;
- ➔ pre-prints of journal articles that were published in restricted journals;

- ➔ theses and dissertations produced by the NAML member country institutions;
- ➔ grey literature – e.g., conference, seminar and workshop papers, operational manuals, speeches, public lectures;
- ➔ conference proceedings;
- ➔ ministry of health technical and research reports;
- ➔ books and book chapters;
- ➔ policy documents from institutions policy documents;
- ➔ archival materials.

Phase 1: Preparation and site visits

The project's first phase comprised site visits by the PIs – who had worked extensively with library systems at regional, national and international level for over 40 years. The PIs and librarians at each site reviewed in detail the various components of the DHR and determined where the strengths and challenges lay. The budget and budget narrative were created at the conclusion of each visit or conference call. In addition to actual equipment and costs of building institutional repositories, the meetings made it possible for on-site peer-to-peer mentoring as well as solid continuation of mentoring amongst the project stakeholders to ensure that skills are transferred and sustained. At the conclusion of each site visit or conference call, budgets and budget narratives were specifically agreed vis-à-vis the librarians' original work plans and the project components to be completed, challenges to be addressed, and the schedule for the release of funds. Prior to the visit or conference call, each librarian provided a completed survey to be used as a baseline.

Phase 2: Implementation of DHRs at five sites

The second phase was the actual building of the DHR that had been agreed to during the site visit, as well as through email and conference calls. Prior to commencement of scanning, a technical expert trained both library and IT staff on the Dspace software. The training addressed the various work flows and the tasks of each person and how to effectively and efficiently carry out tasks without difficulties.

The basic objectives of Phase 2 of the project were the following:

- ➔ Create solid systems for DHRs at each site – this is the ecosystem of people, policies and resources that had been identified during NAML workshops.
- ➔ Educate and engage the university community – from dean/provost to faculty and students as to the importance of the DHR and ensure that a policy is in place regarding archiving requirements.
- ➔ Train library staff, IT personnel, students and faculty members on their roles.
- ➔ Digitize a reasonable amount of archival material from the

university (theses, dissertations, medical journals, reports and publications) and material from the ministry of health (many of which may be in digital form but are not linked to any database for easy access). Current material may already be in digital form and not require scanning, but must be incorporated into DSpace to be made accessible to all.

- ➔ Use Google Scholar or another widely available mechanism to enable free, easy access to the contents of the repository.

Phase 3: Marketing and promotion

From the onset, the DHR planned on conducting advocacy workshops for open access and online publishing among the academic community as well as training researchers and authors to input and retrieve the research output themselves. It is important to market the IRs within institutions and nationally.

Phase 4 - Evaluation of the project

Creating the ADHL is an activity that is self-sustaining, because once the content has been uploaded and the stakeholders have been trained, the project could continue without further funding. The member libraries continuously identified new research and added it to the ADHL. The librarians also mentored fellow librarians and users, and did continuous training of new researchers and authors to ensure updates and continuity of the project. A post-evaluation of the project was carried out by a) designing and sending questionnaires for content submitters and users, and b) generating usage statistics to assess the impact of the ADHL within the member institutions and beyond. Feedback from the questionnaires and usage data are to inform future decisions regarding the progress of the project.

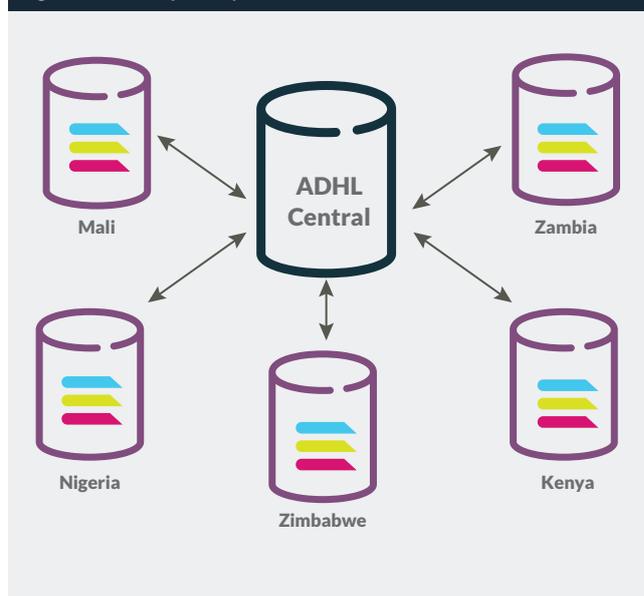
Phase 5 - Sustainability and expansion

- ➔ Mainstream the ADHL into the activities of the university libraries.
- ➔ Use more social media for ADHL promotion.
- ➔ Do an impact assessment and evaluate the collection usage in 2019.
- ➔ Make sure that ADHL becomes an essential service.
- ➔ Establish that each site embeds ADHL into their BAU (business as usual) operations.

Future ADHL architecture

The ADHL will enable access across multiple repositories, probably using a single view. The future for ADHL is one which is integrated, with Open Archives Initiative Protocol for Metadata Harvesting (OAI-PMH) and the Representational State Transfer (REST) based Application Programming Interface (API) that could be used for interoperability between

Figure 2: ADHL repository architecture



the various nodes (countries) and the central node (See Figure 2). Value-added services such as dashboards, Facebook, Google+, Instagram, Reddit, Tumblr, Twitter and YouTube could be incorporated at the central node.

Lessons learned

Several lessons that are critical to the development and success of the digital health repositories were learnt over the course of the project.

- ➔ The training of stakeholders is crucial for the successful implementation of ADHL.
- ➔ The need to work closely with ICT unit, faculty and administrators.
- ➔ Institutional capacity for Dspace and general digital repository principles.
- ➔ Continuous promotion and marketing of the DR to all stakeholders.
- ➔ Advocacy for adoption of Open Access policies by the institutions.

Conclusion

With the initial phases completed, the DHRs are on their way to becoming self-sustaining and the documents in the repositories are freely accessible and available on the Internet. The project has helped to create local partnerships between the medical schools and the ministries of health through the various hospitals across the countries who are the consumers of the information produced. The project has enabled cancer research information sharing among African biomedical researchers locally and regionally. Although project funding came to an end in 2019, the ADHL project will continue. ■

Christine Wamunyima Kanyengo, BA, BSc, MA, is the University Librarian at the University of Zambia. She is a former librarian at the School of Veterinary Medicine and the School of Medicine at the University of Zambia. She holds a BA in Library Studies from the University of Zambia; a Bachelor of Library and Information Science (honours) and a Master of Library and Information Science from the University of Cape Town, South Africa.

Dr Grace Ada Ajuwon, BA, MA, PhD, is a principal librarian (reference and information services) at E. Latunde Odeku Medical Library, College of Medicine, University of Ibadan, Nigeria. She has a BA in Anthropology and a Masters and PhD in Library and Information Science from University of Ibadan, Nigeria. Grace is the pioneer Chairperson of the Network of African Medical Librarians (NAML) and current President of the Association for Health Information and Libraries in Africa (AHILA).

Abdrahamane Anne is a medical librarian at the Faculty of Medicine, University of Bamako, Mali. He is also a lecturer and has been teaching medical students and master of public health students information retrieval and reference management.

Muziringa Masimba is a health librarian, formerly with the University of Zimbabwe. His professional interests include information and knowledge management for health professionals and greater access to health sciences electronic information resources for developing countries.

Nancy Kamau worked at the Kenya Methodist University as the Ag. University Librarian and was the project PI. She is a trained medical librarian who is passionate about information dissemination and has participated in information access and retrieval training forums and scholarly publishing activities. Nancy is a member of the Network for African Medical Librarians. Currently she is working with Health and Knowledge Management Network (HEKMAN).

Justin Maranga Merande is an Information Science graduate and Medical Librarian based at the University of Nairobi Library, College of Health Sciences Library (CHS). He 13 years' experience in providing health information services to healthcare providers. He is

currently the Head of Electronic Resource Training at the College of Health Sciences and PI, ADHL Repository at the University of Nairobi Library.

Nason Bimbe, BSc, MSc, is an experienced software developer, information and knowledge management professional and a specialist in library, learning and scholarly communication, and research information systems with over 15 years' experience. He holds an MSc in Software Development and a BSc (Hons) in Computer Science.

Mercy Wamunyima Monde, BA, MA, is a librarian III at the School of Medicine, University of Zambia. She has 17 years' nursing experience and interests in evidence-based healthcare, particularly in nursing and consumer health information. She holds a Certificate in Nursing from the Lewanika School of Nursing in Zambia, and a Bachelor's and Master's degree in Library Information Science from the University of Zambia.

Celine Maluma Mwafuilwa is a Librarian at the Medical Library of the University of Zambia. She holds a Bachelor of Arts in Library and Information Science and a Master of Library and Information Science from the University of Zambia. As a professional librarian, she joined the University of Zambia Library where she held various senior positions. She is the Acting Head of the Medical library.

Mark Lodge is the Executive Director of the UK branch of the International Network for Cancer Treatment and Research and the Commissioning Editor of Cancer Control 2020

Julia Royall has been working in international health in Africa since 1990 and has more than 40 years of professional experience in the communications field. As Chief of NLM's Office of International Programs, she created innovative programmes that focused on Africa. Now retired from US Government service, she currently serves as principal investigator for the African Digital Health Library (ADHL). She has lectured widely in the US, UK, and Europe, published in Medline-indexed journals, and been honoured for her contributions to global health.

References

- Royall, J. (2017). Email Communication.
- De Mutiis A, Kitchen S. 2016. African digital research repositories: survey report. Africa Bibliography, 2015, Vii-Xxv. doi:10.1017/S02666731160000271.
- University of Zambia. n. d. Institutional Repository. Available at: <http://dspace.unza.zm:8080/xmlui/handle/123456789/5087> [2019, February 24].
- Institute of Development Studies. n. d. Statistics by Country. Available at: <https://opendocs.ids.ac.uk/opendocs/handle/123456789/924/most-popular/country#> [2019, February 24].
- Institute of Development Studies. 2019. Global Open Knowledge Hub. Available at: <https://www.ids.ac.uk/projects/global-open-knowledge-hub/> [2019, February 24].

Cancer Prevention and Treatment

60 Lowering the burden of cancer in a middle-income country: The idealist versus the pragmatist approach

Dr Feisul Idzwan Mustapha and **Dr Arunah Chandran**, Disease Control Division, Ministry of Health Malaysia, Wilayah Persekutuan Putrajaya, Malaysia

66 Evolution of the role of the pharmacist in preventing cervical cancer in low- and middle-income countries

Michelle Asiedu-Danso, Department of Pharmacy Practice and Clinical Pharmacy, School of Pharmacy, University of Ghana, Accra, Ghana; **Kwame Pepreh-Boaitey**, Pharmaceutical Society of Ghana; **Chloe Tuck**, School of Health and Related Research, University of Sheffield, and Commonwealth Pharmacists' Association, London, UK; and **Victoria Rutter**, Commonwealth Pharmacists' Association, London, UK

71 Why an understanding of anthropology is important for cancer control

Carlo Caduff, Reader in Global Health and Social Medicine, King's College London, UK

Lowering the burden of cancer in a middle-income country: The idealist versus the pragmatist approach

Dr Feisul Idzwan Mustapha (left) and Dr Arunah Chandran (right), Disease Control Division, Ministry of Health Malaysia, Wilayah Persekutuan Putrajaya, Malaysia



The lifetime risk for a Malaysian man and woman of developing cancer is one in ten and one in nine, respectively, and the majority of cancer cases in Malaysia are detected late (stage III and IV). While Malaysia relies heavily on World Health Organization (WHO) recommendations on prevention and control of noncommunicable diseases, particularly cancer, we have taken a more pragmatic approach that matches our existing healthcare system, resources and population's needs. The key learning has been the importance of collaboration with a range of stakeholders and building strong partnerships that enable the best use of existing, and often limited, resources and provide opportunities for innovative solutions.

Malaysia is an upper-middle-income country with a population of approximately 32.7 million in 2019. Life expectancy at birth was estimated to be 74.5 years in 2019. Due to rapid urbanization, over 70% of Malaysia's population currently live in urban areas. By 2040, Malaysia is expected to be an "aged" society, with 14.5% of its population aged 65 or older (1). This converging issues have caused a rise in noncommunicable diseases (NCDs), such as cardiovascular diseases and cancer, adding pressure to the already stretched national health system (2).

Malaysia has a two-tier healthcare system. This comprises a tax-funded and government-administered public sector, which offers comprehensive, easily accessible primary-to-tertiary services subsidized for the population, as well as a thriving private sector (3). The majority of the public health services are centrally administered by the Ministry of Health (MOH), which also regulates the public and private healthcare services, pharmaceutical industry and food safety.

The burden of NCDs and current strategies

In Malaysia, NCDs contribute to an estimated 73% of total deaths (4). Premature mortality from NCDs continues to be one of the major development challenges for this country. In response, the first National Strategic Plan for NCD (NSP-NCD) was developed in 2010 by a task force headed by the Director-General of Health Malaysia (5). This was aligned to mandates and resolutions of the World Health Assembly, in particular the 2008–2013 Action Plan for the Global Strategy for the Prevention and Control of NCDs.

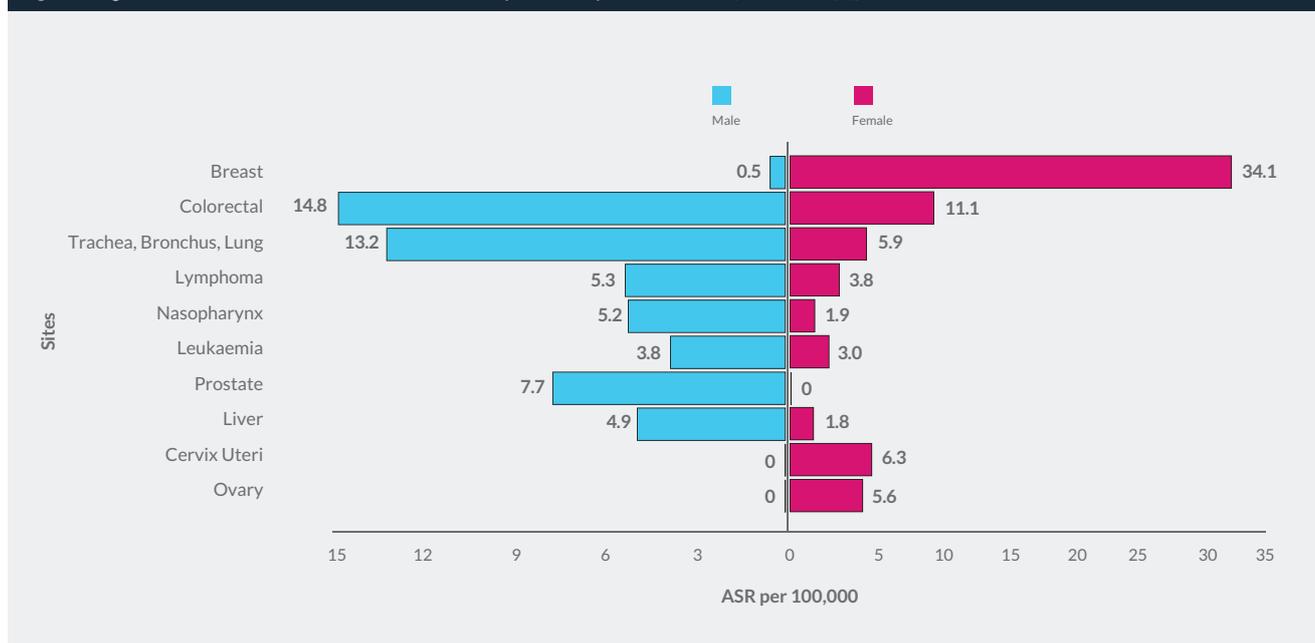
The subsequent NSP-NCD 2016–2025 was also in line with the Global Action Plan for the Prevention and Control of NCDs 2013–2020 (6). The NSP-NCD 2016–2025 was formulated to match the timeline of the nine voluntary global targets for NCDs. It clearly states the NCD targets for Malaysia by the year 2025 and outlined seven specific policies that were formulated to address specific NCD risk factors, utilising the World Health Organization (WHO) "best buys" and "good buys" interventions. In terms of governance, the implementation of policies and regulatory interventions are supported by a Cabinet Committee for a Health Promoting Environment, chaired by the Deputy Prime Minister. One of these specific policies addresses the prevention and control of cancers.

The burden of cancer and the National Strategic Plan for Cancer Control Programme 2016–2020

The Malaysian National Cancer Registry Report 2012–2016 estimated that the lifetime risk of developing cancer for a Malaysian man and a Malaysian woman is one in ten and one in nine, respectively (7). This report found that almost 60% of cancers in Malaysia are detected late (stage III and IV) (7). A study amongst breast cancer patients in Malaysia found that poor breast health literacy, fatalistic fears and external decision-making pressures contributed to delay in presentation (8). Follow-up research is currently ongoing to further understand these barriers and enable more effective interventions.

The 10 most frequent cancers in the general population, males and females in Malaysia, for the period of 2012–2016

Figure 1: Age-standardized rate for ten common cancers by sex, Malaysia 2012–2016 (taken from (7))



are shown in Figure 1 (7). The three most common cancers among males in Malaysia were colorectal (14.8%), lung (13.2%) and prostate (7.7%); whilst the three most common cancers among females in Malaysia were breast (34.1%), colorectal (11.1%) and cervix (6.3%).

The overall objective of the National Strategic Plan for the Cancer Control Programme is to reduce the negative impact of cancer by decreasing the disease morbidity and mortality, and to improve the quality of life of cancer patients and their families (9). The strategies include prevention, screening, early detection, diagnosis, treatment, rehabilitation, palliative care, traditional and complementary medicines, and research and development. In addition, the document acknowledges cross-cutting issues, such as quality of care, surveillance, and monitoring and evaluation mechanisms.

In Malaysia, opportunistic screening services are available for the following four types of cancer: breast, cervical, colorectal and oral cancer. These services are provided in public health clinics throughout the country. Cancer screening for high-risk groups for certain cancers, such as liver, prostate and nasopharyngeal cancer, are conducted as hospital-based screening services. These screenings are also available for a fee in the private setting. In addition, several cancer-related non-governmental organizations (NGOs) conduct breast, colorectal and cervical cancer screening in communities through outreach programmes using mobile screening facilities.

Here, we present Malaysia's approach to primary and secondary prevention of cervical cancer as a case study for the comparison between the strategies and measures that Malaysia has taken (the pragmatist) compared to WHO

recommendations (the idealist).

The idealist

In 2013, the WHO issued a guidance note that formed part of the overall guidance on women's cancer (10). This document was aimed at senior policy makers and programme managers, providing a broad vision of what a comprehensive approach to cervical cancer prevention and control means. It outlined the complementary strategies for comprehensive cervical cancer prevention and control, and highlighted the need for collaboration across programmes, organizations and partners. There is a need to act across the life course using the natural history of the disease to identify opportunities in relevant age groups to deliver effective interventions (Figure 2) (10). The three key WHO recommendations to be implemented at scale in countries are: human papillomavirus (HPV) vaccination, screening and treatment, and treatment of cancer and access to palliative care.

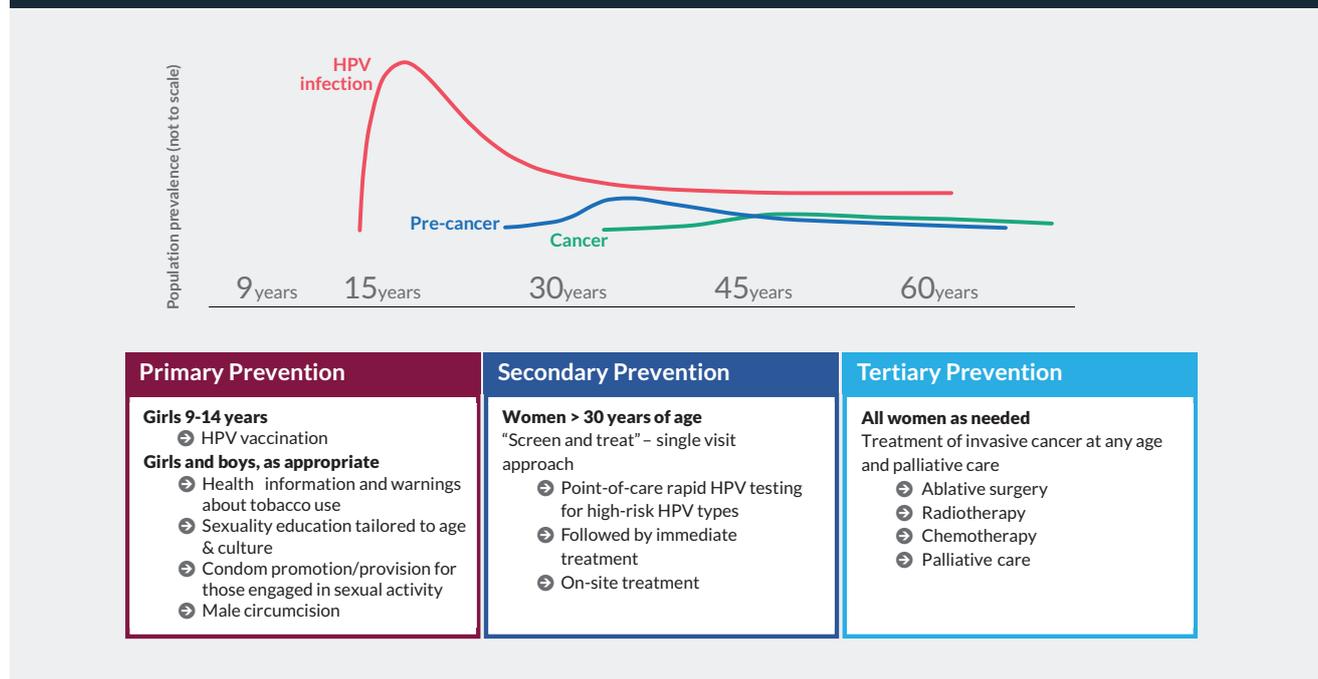
HPV vaccination in Malaysia

The WHO's recommendations are (10):

- two doses for girls aged 9 to 14 years, minimum six months apart.
- introduce to multi-age cohort, aged 9 to 14 years (15 to 18 if feasible) in first year.
- three doses for girls 15 years and older, and for immunocompromized individuals.

The HPV Vaccination Programme in Malaysia was launched in August 2010 and was added to the National Immunization Programme (NIP), which provides selected vaccines free

Figure 2: Overview of programmatic interventions over the life course to prevent HPV infection and cervical cancer (taken from (10))



of charge to all citizens as a public health service (11). The programme used the existing school health services to target girls aged 13 years attending school. The school health service already provides a comprehensive package that includes learning disability assessments; health appraisals, including BMI monitoring, vision screening and thalassaemia screening; and health education. High rates of school enrolment for 13-year olds (96.0%) and retention of female students in secondary schools supported using the school health services (12).

From 2010–2014, each recipient received three doses of HPV vaccine at an interval of 0, 1 and 6 months. From 2015 onwards, two doses of HPV vaccine were introduced (0 and 6 months) following the more recent WHO guideline (13).

At the outset, several major challenges were identified, in particular, poor parental awareness and public confusion; perceived religious and cultural issues; and logistic issues that could delay or disrupt vaccine delivery (14). These were against our existing strengths that included a strong working relationship between MOH and Ministry of Education (MOE) resulting in a good school health services infrastructure and programme; and overall public trust in the NIP. The close working relationship between MOH and MOE enabled efficient coordination of related national policies and corresponding managerial and operational mechanisms (14).

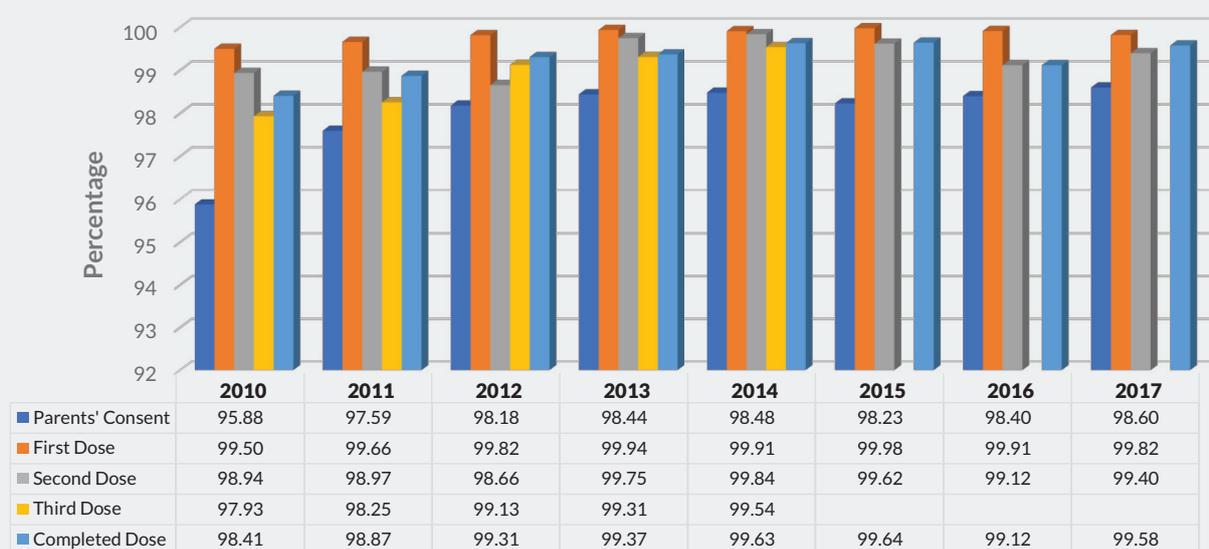
In addressing the challenges, several strategies were employed. First, strategic communication to parents and school children, who were provided with HPV vaccination information through various media platforms. Targeted media campaigns were started early for public awareness. The

campaign featured female students and the key underlying message was to “protect your daughter from cervical cancer”. A comprehensive website was created within the MOH’s MyHealth web portal and this website was linked to all promotional materials. A substantial budget was allocated to secure prime time advertisement spaces. Active media campaigns were sustained for two years from the launch of the vaccination programme. The messages were tailored to local cultural context, religion and information needs of parents, students and the general public to alleviate fear and misconception about the vaccine being new and to reinforce the vaccine’s safety (15).

Second, religious belief-related concerns were also actively addressed. MOH worked closely with the Malaysian religious authority to issue an Islamic ruling (fatwa) on HPV vaccination, addressing concerns about the halal status and the underlying importance and need for this vaccination programme.

Third, the MOH developed a detailed implementation guideline for the programme. The existing relationship between MOH and MOE facilitated obtaining voluntary parental consent through schools. School health nurses delivered talks on HPV infection, cervical cancer and HPV vaccination to the schoolgirls, followed by a health assessment. After the injection, the girls were observed for 20 minutes for any immediate adverse reactions and were subsequently given an Adverse Event Following Immunization (AEFI) monitoring form and vaccination card. All girls were advised to report and seek medical care in the event of any adverse reaction. The AEFI forms were later collected as per the guideline.

Figure 3: Parental consent and HPV vaccination rates in Malaysia, 2010 to 2017 (taken from (14))



Fourth, a robust monitoring and reporting system was also put in place, and this included rumour surveillance from both traditional and social media. A hotline was created at the early stages of implementation to immediately address public concerns. Active AEFI reporting was encouraged and the AEFI monitoring mechanism also had the co-benefit of increasing student and parental awareness of the vaccine and vaccination safety. All negative feedback and reports on HPV vaccination locally and internationally were closely monitored and addressed accordingly.

Lastly, the inclusion of HPV Vaccination into the NIP and the government's commitment to annual funding has ensured sustainability of the programme. Through a transparent national procurement mechanism, MOH secured competitive pricing for the vaccines. At the initial phase of implementation, there was a concerted effort by the private sector to assist MOH in overcoming vaccine transportation and storage constraints, particularly to hard-to-reach places in Malaysia.

In terms of the programme outcome in Malaysia, parental consent for HPV vaccination has been more than 95% from year one of the programme. Of those who consented, the rate of completion of three doses has been more than 98% (15). Population coverage has been more than 80% throughout implementation (Figure 3), despite a decline of four percentage points after a policy change in 2013 that restricted free immunization to public schools. Vaccine wastage has remained low (at 80 of 70,000 doses in 2010), as have adverse events following immunization, which have ranged from 0.06% to 0.45% (15).

Screening for pre-cancer lesions in Malaysia

The WHO's recommendations are :

- women aged 30 to 49 years be screened at least once in their lifetime for cervical cancer, and re-screened every five years.
- HIV-positive women should be screened every three years.
- immediate treatment where possible.

Cervical cancer screening in Malaysia was introduced in 1969, targeting post-partum mothers in family planning programmes in several clinics using the conventional Pap smear screening method. In 1995, the Pap smear screening programme was expanded to women aged between 20 to 65 years. Opportunistic screening is offered by a variety of agencies (MOH, National Population and Family Development Board, university hospitals, private hospitals and clinics, Ministry of Defence and NGOs) but there is no formal registry or a centralized system of cytology laboratories.

The uptake rates are currently estimated to be around 25%, despite media campaigns and the availability of Pap smear services nationwide (16). One study reports that 48% of cervical cancer patients diagnosed at eight major hospitals in Malaysia had never had a Pap smear, while 95% had not had the test within the last three years (17).

A study on cervical screening in Malaysia identified both structural and patient-related factors that contributed to the low uptake (18). Specifically, these included patients' fear, embarrassment, low perceived benefits of screening, inconvenience of procedure (lack of time for clinic visit, discomfort caused by procedure), negative experiences

and low awareness (19). Healthcare-related barriers were lack of space and privacy, lack of trained human resources, and screening infrastructure and support systems. Deeper understanding of behaviours of the population and new or optimized screening methods are required in the context of low- and middle-income countries.

While Pap smear remains as a strategy, the MOH is currently in the process of securing the necessary funding from the Government to shift from Pap smear to self-sampling HPV DNA testing since it has the potential to increase cervical cancer screening rates. A study in Malaysia on the acceptability by women for HPV self-sampling found results that were consistent with other countries, but with some differences (20). More than 90% of women expressed willingness to do self-sampling in the future, however more than half were willing to do the self-sampling at the clinic rather than at home (20). The majority of respondents felt that self-sampling was easy to perform and acceptable.

Programme ROSE (Removing Obstacles to Cervical Screening) is a partnership between University Malaya of Malaysia and VCS Foundation of Australia (21). It is a novel approach to cervical screening that integrates the latest advances in self-sampling, HPV screening and digital health platforms to effectively respond to the needs of Malaysian women. It empowers women to take their own cervical screening sample and have the initial result sent to them via SMS that same day. A pilot implementation in 2018 found that 99% of women were willing to do ROSE again, 95% would recommend it to family and friends, and 94% preferred it to Pap smear screening (22). Reasons given were that ROSE was simple, quick, self-performed, enabled fast results, enabled receipt of results by phone and offered follow-ups and treatment.

Conclusion

As an upper-middle-income country, Malaysia is well positioned to strengthen its response to the increasing burden of NCDs, particularly cancer. For cervical cancer particularly, Malaysia is aligned to the currently proposed 90-70-90 cervical cancer elimination targets by 2030:

- ➔ 90% of girls fully vaccinated with the HPV vaccine by 15 years of age;
- ➔ 70% of women screened with a high-precision test at 35 and 45 years of age;
- ➔ 90% of women identified with cervical disease receive treatment and care.

We must continue to retain vaccine uptake among female students of above 90%. It is also necessary for Malaysia to transition from Pap smear to HPV testing and to institute

a monitoring and surveillance mechanism to achieve 70% screening targets with 90% of abnormal screens being followed up.

While Malaysia often relies heavily on recommendations from WHO, we have taken a more pragmatic approach to match our existing healthcare systems, resources and acceptability of the population. There have been many lessons learned over the years, but the key learning was the importance of collaboration with a range of stakeholders and building strong partnerships. Such collaborations enabled the mobilization and best use of existing, and often limited, resources and provided opportunities for innovative solutions. ■

Disclosure

The authors have declared no conflicts of interest.

Author Contribution

Feisul Idzwan Mustapha and Arunah Chandran: Paper concept, literature search, manuscript preparation and review.

Acknowledgements

The authors would like to thank the Director General of Health, Malaysia for permission to publish this paper. We would also like to acknowledge our colleagues and stakeholders involved in the development and implementation of the HPV Vaccination and Cervical Cancer Screening Programme in the Ministry of Health Malaysia.

This paper was based on a presentation made by Dr Feisul Idzwan Mustapha at the C3 International Breakfast Seminars series in London, on 28 November 2019. Dr Arunah Chandran assisted in preparing the presentation and content.

Dr Feisul Idzwan Mustapha, MBBS, MPH, FAMM, is a consultant public health physician best known for his leadership in prevention and control of noncommunicable diseases in Malaysia. His special areas of interest include diabetes, cardiovascular diseases, cancer and obesity. At the Ministry of Health Malaysia, he is the Deputy Director (NCDs) at the Disease Control Division, where his main roles include policy and programme development, and strategic implementation of interventions for the prevention and control of NCDs. In addition, Dr Feisul has a special interest in leveraging technology to catalyze behavioural modification to reduce the exposure to NCD risk factors.

Dr Arunah Chandran, MD, MSc, MPH, DrPH, is a Public Health Physician at the Ministry of Health Malaysia. Her roles include policy and programme development, and strategic implementation of interventions for the prevention and control of noncommunicable diseases (NCDs). One of her main responsibilities is the Cabinet

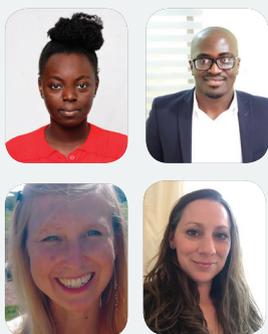
Committee for a Health Promoting Environment, that serves as a platform to identify and discuss multisectoral interventions to create an environment that supports a change in behaviour towards healthier eating and an active lifestyle.

References

1. Department of Statistics Malaysia. Population Projections (Revised), Malaysia 2010-2040. 2019; Available from: https://www.dosm.gov.my/v1/index.php?r=column/cthemByCat&cat=118&bul_id=Y3kwU2tSNVFDOWp1YmtZYnhUeVBEz09&menu_id=L0pheU43NWJwRWVSZklWdzQ4TlhUUT09
2. World Health Organization. Global status report on noncommunicable diseases. 2017, World Health Organization: Geneva, Switzerland.
3. World Health Organization. Malaysia Health System Review, in Health Systems in Transition. 2012.
4. Institute for Public Health, National Health and Morbidity Survey 2015 (NHMS 2015). Vol. II: Non-Communicable Diseases, Risk Factors & Other Health Problems. 2015, Ministry of Health: Kuala Lumpur.
5. Ministry of Health Malaysia, National Strategic Plan for Non Communicable Diseases (NSP-NCD) 2010-2014. 2010, Ministry of Health Malaysia: Putrajaya.
6. Ministry of Health Malaysia, National Strategic Plan for Non-Communicable Diseases (NSP-NCD) 2016-2025. 2017, Ministry of Health Malaysia: Putrajaya.
7. Ministry of Health Malaysia, Malaysia National Cancer Registry Report 2012-2016. 2019.
8. Nors'adah, B., et al., Understanding Barriers to Malaysian Women with Breast Cancer Seeking Help. *Asian Pacific journal of cancer prevention: APJCP*, 2012. 13: p. 3723-30.
9. Ministry of Health Malaysia, National Strategic Plan for Cancer Control Programme 2016-2020. 2016.
10. World Health Organization, WHO guidance note: comprehensive cervical cancer prevention and control: a healthier future for girls and women. 2013.
11. Ministry of Health Malaysia. Immunisation Schedule for National Immunisation Program. 2020; Available from: <http://www.myhealth.gov.my/en/immunisation-schedule/>.
12. Department of Statistics Malaysia. Selected Demographic Indicators Malaysia. 2019; Available from: https://www.dosm.gov.my/v1/index.php?r=column/cthemByCat&cat=397&bul_id=bFhLclp4ZnpSMHRIa21haFNLR2JqZz09&menu_id=L0pheU43NWJwRWVSZklWdzQ4TlhUUT09.
13. World Health Organization. Human papillomavirus (HPV). 2018; Available from: <https://www.who.int/immunization/diseases/hpv/en/>.
14. Muhamad, N.A., et al., Achieving high uptake of human papillomavirus vaccination in Malaysia through school-based vaccination programme. *BMC Public Health*, 2018. 18(1): p. 1402.
15. Buang, S.N., et al., Human papillomavirus immunisation of adolescent girls: improving coverage through multisectoral collaboration in Malaysia. *BMJ*, 2018. 363: p. k4602.
16. Yunus, N.A., H. Mohamed Yusoff, and N. Draman, Non-Adherence to recommended Pap smear screening guidelines and its associated factors among women attending health clinic in Malaysia. *Malaysian family physician: the official journal of the Academy of Family Physicians of Malaysia*, 2018. 13(1): p. 10-17.
17. Othman, N.H., B.C. Devi, and Y. Halimah, Cervical cancer screening: patients understanding in major hospitals in Malaysia. *Asian Pac J Cancer Prev*, 2009. 10(4): p. 569-74.
18. Hong, L.L., et al., Understanding Barriers to Cervical Screening Follow-Up and Treatment Compliance in Malaysia: A Qualitative Study of Provider Perspectives. *Journal of Global Oncology*, 2018. 4(Supplement 2): p. 214s-214s.
19. Seng, L.M., et al., Awareness of cervical cancer among women in Malaysia. *International journal of health sciences*, 2018. 12(4): p. 42-48.
20. Abdullah, N.N., et al., Human Papilloma Virus (HPV) self-sampling: do women accept it? *Journal of Obstetrics and Gynaecology*, 2018. 38(3): p. 402-407.
21. Rose Foundation. PROGRAM ROSE: Removing Obstacles to cervical Screening. 2020; Available from: <https://www.programrose.org/>.
22. Woo, Y.L., The feasibility and acceptability of self-sampling and HPV testing using Cepheid Xpert® HPV in a busy primary care facility. *Journal of virus eradication*, 2019. 5(Suppl 1): p. 10-11.

Evolution of the role of the pharmacist in preventing cervical cancer in low- and middle-income countries

Michelle Asiedu-Danso (top left), Department of Pharmacy Practice and Clinical Pharmacy, School of Pharmacy, University of Ghana, Accra, Ghana; **Kwame Pepreh-Boaitey** (top right), Pharmaceutical Society of Ghana; **Chloe Tuck** (bottom left), School of Health and Related Research, University of Sheffield, and Commonwealth Pharmacists' Association, London, UK; and **Victoria Rutter** (bottom right), Commonwealth Pharmacists' Association, London, UK



Despite being largely preventable, cervical cancer remains a global burden that has a significantly greater impact on low- and middle-income countries where access to prevention services are often limited. This article focuses on perspectives from Ghana and presents challenges and opportunities to address cervical cancer through efficient utilization of existing pharmacy services.

The burden of cervical cancer

The severe inequality in cervical cancer outcomes globally is a public health issue of increasing concern (1). In 2018, cervical cancer cost the world 311,365 lives (2). In low- and middle-income countries (LMICs), it is the second most frequent cause of cancer in women aged 15–44 years (3). Although largely preventable, cervical cancer remains one of the top three causes of death among women in LMICs (4). The primary cause of cervical cancer is persistent or chronic infection with one or more of the “high-risk” types of human papillomavirus (HPV). While most pre-cancerous lesions caused by HPV in women resolve spontaneously, chronic infection with HPV can progress to invasive cervical cancer in some women (7).

The World Health Organization (WHO) estimates HPV infections cause approximately 68,000 cases of cervical cancer each year in Africa (1). However, these figures may be higher due to the challenges in data collection, poor record systems, as a result of the limited capacities of health information systems and established cancer registries.

In Ghana, cervical cancer is the second most frequent cause of cancer among women. It is estimated that every year 3,151 women are diagnosed with cervical cancer, with 2,119 fatalities. Also, the estimated crude incidence rate for cervical cancer in Ghana is 26.4 per 100,000 women per year (5).

According to the Kumasi cancer registry, between the years 2014 and 2016, cervical cancer accounted for 21% of all cancer cases among women. Nartey et al also found the mortality rates of cervical cancer in the Greater Accra region to be 14.7 cases per 1,000 population, and that of the Ashanti region to be 5.3 cases per 1,000 population. Despite a national cancer control plan being established in 2011 (5), challenges remain and very limited progress has been made in dealing with this public health issue. It is estimated that in the West Africa region, about 4.3% of women harbour cervical HPV-16/18 infection at any given time, and 55.6% of invasive cervical cancers are attributed to HPVs 16 or 18 (6). Data is not yet available on the extent of the HPV burden in the general population of Ghana, however, a study in North Tongu District indicated the prevalence may be above that of regional estimates (7).

Approaches for prevention and early detection

There are interventions that exist to prevent, detect or treat cervical cancer across the life course. These include pharmacological approaches, such as vaccines for pre-adolescent and adolescent girls and methods to screen women for pre-cancerous lesions, which can be treated effectively in the clinic to prevent progression to invasive cancer. This is a cost-effective approach to prevent cervical cancer that was

included in the WHO's "best buys" for policy makers to prevent noncommunicable diseases (8).

WHO's comprehensive approach to cervical cancer prevention and control proposes the following measures:

- ➔ an introduction and scaling-up of HPV vaccination;
- ➔ introduction and expanding coverage of routine screening and treatment of pre-cancerous lesions;
- ➔ prompt management of invasive cancers;
- ➔ improving access to palliative care;
- ➔ monitoring using a standard set of indicators and tools to end cervical cancer (4).

WHO's comprehensive approach supports the Sustainable Development Goals (SDGs) relating to ensuring healthy lives and promoting well-being for all at all ages, as well as achieving gender equity and empowerment for all women and girls.

Critical to alleviate the cervical cancer disease burden are approaches for early detection and treatment. The high prevalence of HPV infection in LMICs indicates the need for improving access to effective cervical cancer screening to promote primary prevention and reduce the burden of the disease. Many high-income countries have effectively implemented and sustained population-based screening programmes in tandem with scaling up vaccination programmes to achieve high population coverage. In contrast, screening and vaccination services have been less widely implemented in LMICs due to financial, logistical, access and other socio-cultural barriers (9, 10). Also, inadequate infrastructure, limited health worker training, vaccine cost, cold chain capacity constraints, the stigma associated with HPV as a sexually transmitted infection, the lack of knowledge of HPV infection and vaccination-associated misconceptions and fear of pain and adverse events are major contributing factors to the low coverage of screening and vaccination (11).

The high prevalence of HPV infection in LMICs points to a greater need for improving access to effective cervical cancer screening to promote primary prevention and reduce the burden of the diseases (12, 13). Cost-effective modelling studies have indicated this will be most effective if a wide coverage and uptake is achieved (14, 15). This will, therefore, require embedding access to such services in the community. In many high-income countries, the role of community pharmacists has been explored to varying degrees of success in improving access to screening and prevention (16). Pharmacists as the established "gatekeepers of medicines" have remained vital for the education of both patients and healthcare personnel on medicines and vaccines to ensure safety and efficacy. The role of pharmacists in education, screening, immunization and treatment of cervical cancer has often been overlooked in

LMICs. This has not only limited access to vaccination, but also supply chain efficiency and quality assurance in health delivery.

The evolution of pharmacy roles in public health

Globally, the pharmacy profession has demonstrated dynamism in its roles over the decades, with the introduction of new roles and the extension of its services from the traditional roles of simply dispensing medicines to reporting adverse drug reactions, therapeutic drug monitoring and patient counselling services. This unique quality makes the profession highly adaptable to the times and demands of its clients (patients and health professionals). An area where pharmacists remain underutilized is public health services, including vaccination and immunization. In considering multidisciplinary healthcare professional collaboration towards combating cervical cancer, there are several roles the pharmacist can play, including education, screening, vaccination and cold chain management of vaccines. These roles have been implemented in several high-resource settings, with demonstrated effect. For example, in North America and Europe, pharmacists' role in flu immunization is routine and widespread (17). Community pharmacists in the United States screen for cervical cancer and administer HPV vaccines (16, 18). In several LMICs, like Ghana, pharmacists are actively involved in health advocacy, education, and breast cancer screening through the Pharmaceutical Society of Ghana's Lady Pharmacists Association in the United Kingdom and United States, and oncology pharmacists contribute significantly to cancer management in hospitals and the community. However, these roles remain underutilized in most countries with community pharmacists playing such roles under restricted circumstances. The employment of pharmacists in combating cervical cancer, especially in LMICs, needs to be thoroughly explored to reduce the disease burden.

Pharmacists in cancer prevention

Community pharmacists are one of the few health professionals in constant contact with the community, earning their trust and confidence. The local proximity of community pharmacists to the community they serve places them in the best position to provide access to high-risk persons, including the most deprived. Their nearness makes them the most feasible personnel to provide education, access to HPV self-testing kits and HPV vaccines. However, this approach is not without social barriers to uptake. The accuracy and efficacy of the test is also limited by the capacity of the healthcare professional conducting it (19). Increasingly, self-testing HPV kits are being implemented to offer rapid results at point-of-care (19). In one Ghanaian study, this was provided by community health workers (7). Ghanaian pharmacists could be upskilled to

provide education, access to screening, vaccination and follow-up service to clients at a convenient time and in a trusted community setting. Pharmacists are uniquely positioned for this, given that their training already equips them to ensure quality and safety in medical interventions, and use recording and tracking systems for medicines and patients.

Upskilling has already been piloted in about 30 countries, with some 26 countries incorporating it into their national programmes, often using nurses (20). In the United States and Europe, vaccination, early screening, and testing form a major part of community pharmacy practice (16, 17). Community pharmacists in the European Union (EU) contribute significantly towards the EU vaccination target against influenza and a wide range of public health services (21). Community pharmacies' preferable opening hours and locations mean they play a significant role in reaching those who would otherwise not attend, often the most vulnerable and those subject to health inequality. The advantages of having community pharmacists administer influenza vaccines can be translated to the administration of HPV vaccines in LMICs, as is routine in most states in the United States (22). This contributes significantly to curbing the cervical cancer burden. The potential advantages of community pharmacists administering the HPV vaccine in LMICs like Ghana are immense, but as yet untapped.

Feasibility in Ghana

The Pharmacy Council 2018 data estimates approximately 2,500 community pharmacies in Ghana who provide different services to their communities. A study conducted by Karikari-Agyeman et al (2017) demonstrated community pharmacist's willingness and readiness to participate in immunization and vaccination services in Ghana (23). The study explored the perspective of the stakeholders and regulators on the suitability of the use of community pharmacies for immunization services. The findings highlighted additional training, a review of the legal framework as an important consideration to facilitate pharmacists' involvement in providing services, including the delivery of HPV. The Pharmacy Council makes provisions for pharmacists to be involved in activities such as immunization provided they have received the required training and certification (23). The introduction of the Doctor of Pharmacy programme provides an additional potential for pharmacists in Ghana to deliver these services. The Doctor of Pharmacy programme was introduced in 2012. The programme offers a more patient-centred training to students and saw the graduation of 132 students in the first batch. These numbers have increased exponentially as more universities have rolled out the programme. The programme prepares students

to be clinically oriented and prepared to meet the needs of patients in terms of vaccination, patient counselling and drug monitoring.

Since the introduction of the HPV vaccine in 2006, few women in LMICs like Ghana, where the incidence and mortality rates are highest, have been vaccinated. Just 1% out of 59 million vaccinated women in the world are from a LMIC (24). A study carried out by Adageba et al, showed that there was very low knowledge of screening locations among some women in Ghana (25). This highlights the role of pharmacists in increasing the locations of education sources and prevention centres for women in Ghana. Community pharmacies provide proximity, close patient-personnel relationships and extended hours of operation which are crucial support frameworks required for the completion of multi-dose vaccines like the HPV vaccine. This unique role is being underutilized, putting more Ghanaian women at risk of cervical cancer every day. In Ghana, the Lady Pharmacists' Association (LAPAG) currently plays a key role in breast cancer awareness and screening exercises. This has been done in specific pharmacies and special outreach activities ensuring the privacy of the women. Their activities have also involved interacting with women in different social settings and sharing with them critical information concerning their health in general and breast cancer. These social settings include schools, faith institutions such as churches and sometimes market spaces. The awareness sessions are often held in groups, while screening and further counselling takes place on an individual basis and under strict patient confidence. Referrals are made to the closest treatment centre based on the location and preference of the patient, for the hospital to follow up with treatment. Extending these services to cover cervical cancer would be feasible if LAPAG members and pharmacists are provided with training and resources.

Harnessing digital innovation for cancer prevention through pharmacies

The services and skills of pharmacists could be synergized with information communication systems given the widespread use of mobile technology. Telecommunication companies have been utilized to send out public health messages and could be used to send reminders and connect women and young girls in communities to the nearest pharmacy where screening and vaccination are conducted. This has been explored by Family Health International (FHI360-Ghana) in its community-based hypertension improvement project. Similar strategies have been explored in Rwanda, Zambia and South Africa through telehealth for cervical cancer screening and care to sensitize women to get screened and start treatment where necessary. This tricycle relationship serves to benefit all parties involved

while eliminating cervical cancer. Most women do not seek screening because of a lack of awareness and myths surrounding the disease, testing and treatment (25). Education in the community, delivered by pharmacists could seek to correct this situation and improve health-seeking behaviour of community members. This not only evolves the traditional roles of pharmacists to meet the digitalized world, but serves to bring the pharmacist closer to the patient.

Pharmacists in quality accuracy at point of access

One important aspect of the success of any vaccination programme lies in cold chain management. The pharmacist is recognized as the expert in this. In Ghana, the importance of the pharmacist in the maintenance of medicines cold chain cannot be overemphasized. Effective cold chain management is crucial for HPV vaccine quality assurance. As pharmacists become involved in the vaccination process, the maintenance of the cold chain can be better supervised; especially in remote areas where storage may be prolonged before use, the pharmacist's expertise is crucial. A study jointly conducted by the Pharmacy Council and Pharmaceutical Society of Ghana with the support of Management Sciences for Health (MSH) shed more light on this. The study showed the dire need for pharmacists' integration in the cold chain maintenance of drugs during transportation and storage (26). In such systems and processes, the community pharmacist can make a significant contribution, particularly in relation to maintaining the cold chain until the use of the HPV vaccine, ensuring patients receive only viable vaccines.

Contemporary concerns and challenges

In the present situation, concerns around profit-led motivations overtaking the ethical senses of pharmacists have often been raised. For example, customer demands and profits have been indicated to drive antibiotic dispensing in Tanzania (27). A strong regulatory procedure can safeguard against this. For instance, (i) adopting licensed centres into the national health insurance scheme will reduce the cost burden from the patient and further increase access; (ii) only registered facilities where due training of personnel at the facility has been carried out may undertake screening and vaccination. The setting up of protocols can also be established to guide pharmacists in implementing approaches. Such regulatory measures have been established in most states in the United States, where only approved community pharmacies with trained pharmacists are permitted to carry out screening and vaccinations. In these states, screening and treatment are carried out according to national and state guidelines.

Contrary to these concerns, pharmacists are an extremely

underutilized resource and the potential to work harmoniously with small-scale pharmacy businesses is an untapped asset. Community pharmacies in Ghana are self-sustaining and employ pharmacists without requiring government funding. Funding models could be established to provide reimbursement in return for the delivery of specific national health insurance services which would not necessarily require additional workforce investment by governments. This poses both a highly feasible and sustainable proposition for implementing a nationwide HPV plan.

Concluding remarks

Amplifying the role of pharmacists as medical representatives through training to screen and treat HPV, act as a source of readily available information and effectively store vaccines is a crucial first step and a key opportunity for multisectoral collaboration, towards the common goal of eliminating cervical cancer. Pharmacists from almost all spheres of practice can play a significant role in reducing the cervical cancer burden. In settings where resources are limited, their roles are multiple and key. Their community contribution to the education of girls and women on cervical cancer and reproductive health, screening, and vaccination of especially high-risk patients, as well as supply regulation to ensure proper use and storage of vaccines are vital.

The role and inclusion of the community pharmacist in cancer control and care has been omitted for far too long (28). The day and age has arrived for the evolution and inclusion of the pharmacist, especially the community pharmacist, in oncology management of cervical cancer. ■

Acknowledgements

The authors would like to show their gratitude and appreciation to Dr Rev. Dennis Sena Awitty and Yvonne Yirenyiwa Esseku from Pharmaceutical Society of Ghana and Ghana College of Pharmacists respectively for kindly reviewing drafts of the article.

*Michelle Asiedu-Danso, BPharm, is a pharmacy practice and clinical pharmacy researcher at the School of Pharmacy, University of Ghana. After graduating from the University of Ghana School of Pharmacy, Michelle has continued to work as a part-time research and teaching assistant. She has co-authored papers including "Complementary and alternative medicine use for primary dysmenorrhea among Senior High" (published in the *Obstetrics and Gynecology International Journal* (2019)) and "The pharmacist's voice on medication adherence in African newspapers: missing or prominent" which was presented at the *International Federation of Pharmacist Conference* (2019, Abu Dhabi). She enjoys exploring different perspectives to foster*

innovation across health-related disciplines.

Kwame Peprah Boaitey, B Pharm, MSc Global Health, is a global health consultant and a pharmacist, with interest in antimicrobial stewardship, antimicrobial resistance, access to medicines, drug utilization and health policy. His passion is to promote and harness pharmacists' potential in addressing public health issues affecting low- and middle-income countries. Kwame has a Masters in Global Health from Karolinska Institute in Sweden and a Certificate in Pharmaceutical Policy Analysis from Utrecht University.

Chloe Tuck, Mbiochem, is a PhD candidate in Public Health, Economics And Decision Science at the School of Health and Related Research, University of Sheffield, UK; and Advisor, Commonwealth Pharmacists' Association. Passionate about addressing barriers to health globally, Chloe's research takes systems-wide approaches to understand how decision making can support policies for greater health equity. With a background in project management, she managed the evidence synthesis and technical input for the

inception of the Commonwealth Partnerships for Antimicrobial Stewardship programme to share and apply knowledge between the UK and four African countries. Chloe has a Masters in Biochemistry from Oxford University.

Victoria Rutter, MPharm, PGDipClinPharm, FFRPS, MRPharmS, Master Practitioner of NL has worked as a clinical pharmacist in flagship hospitals in London and Singapore. She has an extensive portfolio of clinical practice activities, with a special interest in service improvement, professional development and post-graduate training. She is widely recognized for her involvement in the global pharmacy professional development arena. As executive director of the Commonwealth Pharmacist's Association, her work is focused on antimicrobial resistance (AMR), substandard and falsified medicines and provision of accessible and affordable continuing education. Victoria was responsible for pioneering the Commonwealth Partnerships in Antimicrobial Stewardship scheme (CwPAMS) to help share expertise in tackling AMR across international boundaries.

References

1. Cervical cancer common amongst African women | WHO | Regional Office for Africa [Internet]. [cited 2020 Jan 5]. Available from: <https://www.afro.who.int/news/cervical-cancer-common-amongst-african-women>.
2. Bray F, Ferlay J, Soerjomataram I, Siegel RL, Torre LA, Jemal A. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin*. 2018;68(6):394–424.
3. Ginsburg O, Bray F, Coleman MP, Vanderpuye V, Eniu A, Kotha SR, et al. The global burden of women's cancers: an unmet grand challenge in global health. *Lancet*. 2017 Feb 25;389(10071):847–60.
4. WHO | Cervical cancer [Internet]. WHO. [cited 2020 Feb 8]. Available from: <http://www.who.int/cancer/prevention/diagnosis-screening/cervical-cancer/en/>.
5. Ghana Ministry for Health. National Cancer Control Plan for Ghana [Internet]. 2011 [cited 2020 Feb 16]. Available from: <https://www.iccp-portal.org/system/files/plans/Cancer%20Plan%20Ghana%20Ministry%20of%20Health.pdf>.
6. HPV INFORMATION CENTRE [Internet]. [cited 2020 Feb 9]. Available from: <https://www.hpvcentre.net/>.
7. Krings A, Dunny P, Pesic A, Tetteh S, Hansen B, Gedzah I, et al. Characterization of Human Papillomavirus prevalence and risk factors to guide cervical cancer screening in the North Tongu District, Ghana. *PLoS One* [Internet]. 2019 Jun 27 [cited 2020 Feb 16];14(6). Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6597158/>.
8. World Health Organization. WHO Best buys for NCDs [Internet]. World Health Organiza; 2011 [cited 2020 Feb 16]. Available from: <https://apps.who.int/iris/bitstream/handle/10665/259232/WHO-NMH-NVI-17.9-eng.pdf;jsessionid=5AA3AA8A45A20B5A240764BF9B8DDDE9?sequence=1>.
9. Magrath DI, Ghebreyesus DTA. Cancer care in emerging health systems. *Cancer Control*. 2019;103.
10. Black E, Richmond R. Prevention of Cervical Cancer in Sub-Saharan Africa: The Advantages and Challenges of HPV Vaccination. *Vaccines (Basel)* [Internet]. 2018 Sep 8 [cited 2020 Jan 6];6(3). Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6161067/>.
11. Graham JE, Mishra A. Global challenges of implementing human papillomavirus vaccines. *Int J Equity Health*. 2011 Jun 30;10:27.
12. Prevention of Cervical Cancer in Sub-Saharan Africa: The Advantages and Challenges of HPV Vaccination [Internet]. [cited 2020 Jan 5]. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6161067/>.
13. Goldie SJ, Gaffikin L, Goldhaber-Fiebert JD, Gordillo-Tobar A, Levin C, Mahé C, et al. Cost-effectiveness of cervical-cancer screening in five developing countries. *N Engl J Med*. 2005 Nov 17;353(20):2158–68.
14. Campos NG, Castle PE, Wright TC, Kim JJ. Cervical Cancer Screening in Low-Resource Settings: A Cost-Effectiveness Framework for Valuing Tradeoffs between Test Performance and Program Coverage. *Int J Cancer*. 2015 Nov 1;137(9):2208–19.
15. Campos NG, Tsu V, Jeronimo J, Mvundura M, Lee K, Kim JJ. To expand coverage, or increase frequency: Quantifying the tradeoffs between equity and efficiency facing cervical cancer screening programs in low-resource settings. *Int J Cancer*. 2017 15;140(6):1293–305.
16. Havlicek AJ, Mansell H. The community pharmacist's role in cancer screening and prevention. *Can Pharm J*. 2016 Sep;149(5):274–82.
17. Pharmacy: a way forward for public health. *A Way Forward*. :53.
18. Pharmacists' Role in Preventing Vaccine-Preventable Diseases [Internet]. [cited 2020 Jan 6]. Available from: <https://www.uspharmacist.com/article/pharmacists-role-in-preventing-vaccine-preventable-diseases>.
19. Toliman PJ, Kaldor JM, Tabrizi SN, Valley AJ. Innovative approaches to cervical cancer screening in low- and middle-income countries. *Climacteric*. 2018;21(3):235–8.
20. Cubie HA, Morton D, Kawonga E, Mautanga M, Mwenitete I, Teakle N, et al. HPV prevalence in women attending cervical screening in rural Malawi using the cartridge-based Xpert® HPV assay. *Journal of Clinical Virology*. 2017 Feb 1;87:1–4.
21. European Commission, Directorate-General for Health and Food Safety, Expert Panel on effective ways of investing in Health (EXPH). Vaccination programmes and health systems in the European Union. [Internet]. 2018 [cited 2020 Feb 9]. Available from: <http://dx.publications.europa.eu/10.2875/18503>.
22. Dingman DA, Schmit CD. Authority of Pharmacists to Administer Human Papillomavirus Vaccine: Alignment of State Laws With Age-Level Recommendations. *Public Health Rep*. 2018 Jan 1;133(1):55–63.
23. Karikari-Agyeman B. Feasibility and Acceptability of the Use of Community Pharmacies as Service Points for Immunisation in the Accra Metropolitan Area. [Accra]: University of Ghana; 2017.
24. Bruni L, Diaz M, Barrionuevo-Rosas L, Herrero R, Bray F, Bosch FX, et al. Global estimates of human papillomavirus vaccination coverage by region and income level: a pooled analysis. *Lancet Glob Health*. 2016;4(7):e453–463.
25. Adageba RK, Danso KA, Ankobea FK, Kolbilla DZ, Opoku P. Knowledge of cervical cancer and patronage of cervical cancer screening services among female health workers in Kumasi, Ghana. In 2011.
26. Peprah-Boaitey K. Gaps in pharmaceutical service delivery in the upper west region of Ghana [Manuscript in preparation]. 2020.
27. Horumpende PG, Sonda TB, Zwetselaar M van, Antony ML, Tenu FF, Mwanziva CE, et al. Prescription and non-prescription antibiotic dispensing practices in part I and part II pharmacies in Moshi Municipality, Kilimanjaro Region in Tanzania: A simulated clients approach. *PLOS ONE*. 2018 Nov 21;13(11):e0207465.

Why an understanding of anthropology is important for cancer control

Carlo Caduff, Reader in Global Health and Social Medicine, King's College London, UK



Anthropology has a key role to play in implementing cancer control programmes in low- and middle-income countries through uncovering the local realities and real-life experiences behind those suffering with cancer to create more appropriate strategies to beat the disease. As the article shows, interviewing techniques can be all important in finding out the truth.

Anthropology is a social science using a wide range of social science research methods to understand the ways in which people live in different social, cultural and political settings and how they perceive the world around them. Contrary to other social science disciplines, it is based on a commitment to long-term empirical research in local settings.

The rising incidence of cancer that many low- and middle-income countries are facing today is raising substantial social, political, technological and economic challenges. Low-quality primary healthcare means that people are more likely to be diagnosed with advanced disease. While receiving treatment, poor patients often have to live outdoors because they cannot afford accommodation. Lack of regulation and accountability and a rapidly expanding private healthcare industry facilitate the over-use of diagnostic and therapeutic interventions. These and other challenges require research that goes beyond the traditional biomedical-clinical nexus.

Implementing adequate cancer control programmes in low- and middle-income countries without understanding the conditions on the ground is a recipe for failure. What we urgently need today are systematic studies of local realities and real-life experiences that create opportunities to empower change and improve cancer control. Equally urgent is a collaborative form of research that can elicit the patient's voice and that can provide us with the necessary means to understand it. This means that we need to put the emphasis on structures and strategies rather than relying on a reductionist model of individual behaviour that often blames people for their illness.

Because of its emphasis on local conditions, anthropology can provide us with a better understanding of how oncology can be practiced in a radically different setting, often marked by diversity, complexity and massive therapeutic disparity. Anthropology can also help us move beyond research and

policy agendas that are frequently driven by the concerns and priorities of high-income countries.

Talking about cancer

Cancer is a topic that many prefer to avoid. The disease is often surrounded by silence. This makes it a challenging subject for social science research. How to study a disease that is frequently denied, repressed and concealed? As part of a research collaboration with Tata Memorial Hospital in Mumbai, India we conducted semi-structured interviews with 400 patients and family members. In these interviews, we asked open-ended questions focused on the accessibility and affordability of cancer care in India. All interviews were conducted in Tata Memorial Hospital between October 2017 and April 2018. For the research, we received approval from the Institutional Ethics Committees of Tata Memorial Hospital, in addition to approval by the Indian Council of Medical Research of the Government of India. The interviews were conducted in Hindi, Bengali, Marathi and English, depending on the preferred language of participants.

To showcase anthropological research and highlight some of the challenges of knowing cancer, this article presents an excerpt from an interview with a farmer from Maharashtra. In this interview, we asked whether there had been other cases of cancer in the family, neighbourhood or village.

Q: Did you ever hear the name of cancer? Or did anyone have it in your house?

A: No, never heard it.

Q: Did you ever hear the name?

A: No, never. First time.

Same interview with the same person after 20 minutes and questions about other topics.

Q: And [has] this kind of big disease [cancer] [occurred] anywhere in your family or village?

A: No.

Q: What is the kind of perception about this disease in your village?

A: In my village, this disease hasn't happened to anyone. Not to anyone as yet.

After 30 minutes and questions about other topics.

Q: You have been here for so many days. You know it's a cancer hospital; do you ever get scared if you get a pain in your body?

A: Yes. Earlier I used to feel so. In the beginning, when I came, I used to feel so. It's a cancer hospital. There was a man from my village who brought his son here. He also had cancer. Of the bone. Everything was good for them. They were here for one and a half years. Recently, they returned to the village. They had all kinds of facilities here. It was a child. They were given all facilities. Now they have left. They said it's good. You don't have to take any tension.

After 35 minutes and other questions about other topics.

Q: Did you hear the name cancer before?

A: Yes. cancer, I had heard the name. My uncle had cancer. He died.

Q: Your real uncle?

A: Yes.

Q: What kind of disease?

A: It was here, in the mouth.

Q: He must have been eating tobacco.

A: He ate tobacco and he also drank alcohol. We took him to Aurangabad. They burnt it [radiation]. Then, we brought him to our village. For 2–4 days, he was fine. Later, he thought that his disease is fine now. He started drinking again. He died.

How did we get to know what we wanted to know? By starting a conversation and letting the person speak until we got the whole story. As anthropologists know, an initial response to a question often gets revised in the course of a conversation. This raises the following question: Can we know something about understandings of and experiences with cancer if we don't give people enough time and space to express themselves? How robust and reliable are cancer awareness studies really, especially when they are based on surveys?

Anthropologists place methodological emphasis on observation, indirect questioning and redundancy (asking the same question in different ways again and again). Observation, indirect questioning, and redundancy can produce more

robust and reliable evidence. This is important because the first response to a question is often not the most accurate one. The truth is not on the surface.

Because of its complex mode of existence in people's lives, cancer is particularly difficult to study from a social science perspective. Information can frequently be arrived at only indirectly. Accordingly, the most suitable combination of methods promising the most robust and reliable data is a mixed methods approach that includes open-ended questions. Only a mixed methods approach is able to reveal the risk of incomplete and sometimes misleading information emerging from survey data.

Conclusion

Given the rising incidence of cancer and the lack of adequate treatment and prevention, we need high-quality social science research to build a reliable and robust evidence base for cancer control programmes in low- and middle-income countries. We need approaches that go beyond the surface, that take into account the silences around the disease, and that can humanize and add richness to our understanding of cancer in heterogeneous and complex settings. There is an urgent need for empirically grounded, high-quality social science research in settings where social, political and economic forces are major causes of poor treatment outcomes. Cancer control programmes in low- and middle-income countries must be based on a robust and reliable understanding of local realities and lived experiences. Everything else is a recipe for failure. ■

Carlo Caduff is Reader in Global Health and Social Medicine at King's College London, Director of Postgraduate Research Studies and Chair of the Culture, Medicine and Power research group. His research examines the social, cultural, political, technological and economic dimensions of cancer care in India.

He is also Principle Investigator of the Grid Oncology Wellcome Trust project, a five-year collaborative research programme on the changing landscape of cancer care in India. The focus is on the decentralization, standardization, and digitalization of oncology for the benefit of patients.

Dr Caduff is an affiliate of King's India Institute and Visiting Faculty at the Graduate Institute Geneva. With colleagues at King's, Harvard and Johns Hopkins, he launched the Global Social Medicine Network to link, support, and build upon existing interdisciplinary social medicine programmes across the world.

Dr Caduff received his PhD in Anthropology from the University of California at Berkeley.

International Network for Cancer Treatment and Research (INCTR) Update



74 Mission, organization and achievements

77 INCTR Branches

78 INCTR Governing Council and partner institutions in developing countries

78 Partners: Past and present

Mission, organization and achievements

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

The need for INCTR: Cancer in developing countries

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

Resources of all kinds for treating cancer are limited in LMICs, such that patients who develop cancer frequently lack access to a facility capable of making an accurate diagnosis and providing appropriate therapy. There is a lack of drugs, a paucity of radiation therapy facilities and very few cancer specialists or other health care workers who are needed to effectively care for cancer patients. Diagnosis may be so delayed that there is little that can be done even if the patient does finally reach a facility competent to care for them. Terminal care is not widely available, and regulations and attitudes are still largely directed towards preventing the misuse of opioids rather than relieving the pain of dying patients, such that most patients die without symptomatic relief or little or no mental or spiritual comfort. It is estimated, for example, that less than 1% of patients who need palliative care in India receive it.

INCTR is unique in that it focuses only on the developing world. It also works directly with its collaborators, sometimes

visiting them many times in order to achieve its goal of helping to build sustainable capacity in LMICs in order to assist these countries in cancer prevention, early diagnosis, treatment and palliative care. It is not an advocacy organization, and all clinical projects are coordinated by a health professional. Its output is information collected in the field, lives saved by cancer prevention or treatment, and improved quality of palliative care.

Who INCTR works with

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

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

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

INCTR integrates research into its programmes by documenting and evaluating actual data (rather than projected economic or health benefits, for example). Such research may include a wide range of projects, from cancer education for the general public to developing treatment outcomes, including palliative care. This, in turn, enables healthcare professionals working in LMICs to become familiar with the most pressing issues and to develop plans to improve efficiency and reduce cost. Although clearly many countries have limited health workforces and quantitation of such workforces can be valuable in terms of planning for the future, it realizes that many cancer plans have little impact because of the limited resources and great difficulty in expanding interventions to very poor populations which cannot “purchase” their own healthcare needs and which have little or no chance of expanding their present resources. Having a cancer plan is not enough. Successful cancer plans require knowledge and a budget in addition to educated health professionals.

INCTR's structure

INCTR has consultants and volunteers dedicated to the

INCTR'S GOALS – MAKING A DIFFERENCE

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

Figure 1: Disease burden and resources



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

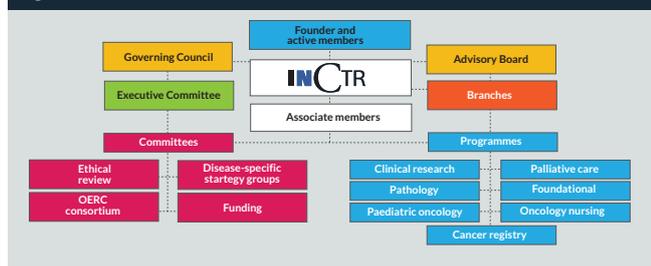
Resource development, administration and programmes (e.g., adult oncology, paediatric oncology, cancer registries, pathology and palliative care) are supervised by an Executive Committee or directly by the branches. The Executive Committee is responsible to INCTR's Governing Council. Programmes and projects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

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

What does INCTR do?

INCTR addresses all aspects of cancer control with the overall goal of lessening the morbidity and mortality from cancer. It emphasizes training and education of healthcare professionals in LMICs to ensure that "best practices" are instilled in cancer prevention, early diagnosis, treatment and palliative care. Research is an integral part of its work with its partners in LMICs in order to accurately document the cancer burden – including the types of cancer and extent of disease, the outcomes of prevention and early detection campaigns and the efficacy, toxicity and cost of treatment delivered. It also emphasizes public awareness

Figure 1: Disease burden and resources



STRATEGIES

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

of cancer, which is an essential component of early diagnosis. INCTR has a variety of programmes that are carried out in close collaboration with its branches as well as its partner institutions in developing countries. INCTR's current programmes include:

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

INCTR's projects and achievements

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

Adult oncology

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

Cancer registries

- ➔ Establishing an East African Registry Network (EARN) that subsequently became the African Cancer Registry Network (AFCRN). As part of the Global Initiative for Cancer Registry Development in LMICs, the Network acts as a consortium to provide a "regional hub" for cancer registries in sub-Saharan Africa. The AFCRN is supporting or assisting the development of 22 cancer registries in the region, including English- and French-speaking countries.
- ➔ Provision of training courses in cancer registration and the use of CanReg 5.
- ➔ Participation in collaborative international research.
- ➔ Visits of INCTR consultants to the Kingdom of Saudi Arabia to review cancer registration procedures and data quality and to Uganda to offer advice on setting up a cancer registry.

Clinical research

- ➔ The treatment and characterization of acute Lymphoblastic Leukemia in children, adolescents and young adults in India –

over 450 patients have been treated by four institutions.

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

Foundational

- ➔ Accreditation Programme in the conduct of clinical trials in institutions in Brazil.
- ➔ Educating school children about cancer in Nepal.
- ➔ Evidence-based development through preparation of bibliographies of published literature from developing countries relevant to breast cancer and selected cancers in Egypt.
- ➔ Open Educational Resources for Cancer available online.
- ➔ Thematic workshops to discuss challenges in cancer control in East Africa.
- ➔ Webinars for e-learning.
- ➔ Publication of five annual editions of *Cancer Control* from 2013, with specialist healthcare publisher, Global Health Dynamics, looking at all aspects of cancer policy, prevention, detection, treatment and palliation.

Palliative care

- ➔ Training and educating healthcare professionals – doctors, nurses and social workers in the principles of palliative care – in Brazil, Cameroon, Burkina Faso, Sénégal, Mali, Tanzania, India and Nepal.
- ➔ Sensitization workshops for government officials and the public in Brazil, Tanzania, India and Nepal.
- ➔ Development of a centre of excellence in palliative care for both adults and children in Hyderabad, India.
- ➔ Lobbying governments to improve access to opioids for terminally-ill cancer patients – Nepal and India.
- ➔ Establishment of twinning programmes with hospices in Canada that support palliative care efforts in Nepal.
- ➔ Fostering the establishment of palliative care societies – in

Nepal and Pakistan.

- ➔ Promoting paediatric palliative care in Pakistan.
- ➔ Publishing a palliative care handbook describing the management of a wide variety of symptoms in English, Portuguese, French and Turkish.
- ➔ Development of the “Life at Your Doorstep” home care programme offering extensive, 24/7 support for patients and families struggling with advanced and terminal illness in the cities of Hyderabad and Secunderabad.
- ➔ Organized training course for Francophone sub-Saharan Africa in Uganda. This was led by HASPF and the Institute of Hospice and Palliative care in Africa with expert input by Hospice Africa Uganda and Alliance Mondiale Contre le Cancer.
- ➔ Palliative care workshops and training courses for Francophone sub-Saharan Africa organized by AMCC in partnership with AFSO were held in Uganda and Ivory Coast.
- ➔ Establishment of palliative care centres of reference and training in sub-Saharan Francophone Africa (Mali, Cameroon, Ivory Coast).
- ➔ Canadian branch provides training in India for St Mary Hospital in palliative care and fosters a collaborative approach between palliative care and health care in Nepal.
- ➔ Development of palliative care programme in Rajasthan, India.

Paediatric oncology

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

Pathology

- ➔ Central pathology review of Burkitt Lymphoma in institutions participating in the treatment protocol for this disease in

Africa.

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

Psychosocial support

- ➔ Development of an educational programme relating to the psychosocial needs of cancer patients in conjunction with the Brazilian Society of Paediatric Oncology.

World Health Organization

- ➔ Organized the 2009 update of the WHO Essential Medicines

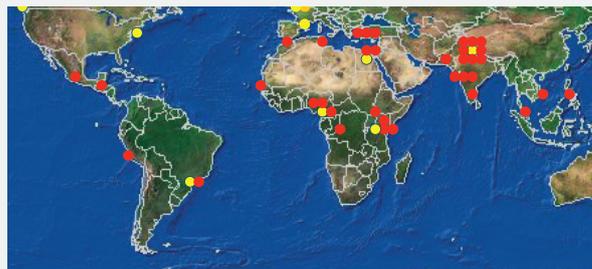
List for Cancer.

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

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

INCTR Branches

Branches are established as legal non-profit organizations within the country in which they are located so that they may raise and disburse funds in support of INCTR’s mission. Branches establish and maintain linkages with cancer centres or units, relevant professional organizations or elements of national or regional governments and coordinate ongoing INCTR programmes and projects within the country or region, if located in a low- and middle-income country. INCTR branches are listed below.

**BRAZIL**

INCTR Brazil
Associação Internacional para Tratamento e Pesquisa do Cancer
Av Nove de Julho, 4275
Jardim Paulista, CEP 01407-199
São Paulo, SP, Brasil
➔ President: Dr Sidnei Epelman
Contact: inctr@inctrbrasil.org

CANADA

INCTR Canada “Two Worlds Cancer Collaboration”
401–41 Alexander Street
Vancouver, British Columbia
V6A 1B2 CANADA
➔ President: Dr Simon Sutcliffe
➔ Treasurer: Dr Stuart Brown
➔ Secretary: Dr Fraser Black
Contact: cci-cancercontrol@shaw.ca
or Helen@torrance.com

EGYPT

INCTR Egypt
First Floor, app 10
2 Houd El Laban Street
Garden City, Cairo, Egypt
➔ President: Dr Hussein Khaled
➔ Executive Director: Dr Atef Badran
Contact: atef.badran@gmail.com

FRANCE

Alliance Mondiale Contre le Cancer
Institut Curie, 26 Rue D’Ulm
75005 Paris, France
➔ President: Professor Martine Raphaël
➔ Medical Director: Professor Pierre Bey
➔ Treasurer: Professor Jacques Rouëssé
➔ contact@cancer-amcc.org

INDIA

INCTR India
Swasthya Kalyan Bhawan
Narin Singh Road, Jaipur
302004 Rajasthan, India
Trustees:
➔ Dr Shivraj Singh (Managing Trustee)
➔ Mr Apurv Kumar
➔ Mr Rajiv Sahai

NEPAL

Nepalese Network for Cancer Treatment and Research INCTR
Nepal Ghokechaur Banepa 1, NEPAL
➔ Chairman: Dr Surendra B B Shrestha
➔ Vice Chairman: Dr Manohar Lal Shrestha
➔ Member Secretary: Radha Pyari Nakarmi
Contact: nnctr@ntc.net.np

UNITED KINGDOM

INCTR Challenge Fund
267 Banbury Road
Prima House, Oxford OX3 7HT
United Kingdom
Contact: max.parkin@ctsu.ox.ac.uk
➔ Chairman: Dr Max Parkin
➔ Administrator: Mrs Biying Liu
Contact: bliu@afcm.org

UNITED STATES

INCTR USA
5111 Ambergate Lane
Dallas, Texas
75287 -5405
USA
➔ President and Chairman:
Dr Madhavan Pillai
For information: info@inctr.be

Governing Council

Dr Sultan Al-Sedairy

Vice President for Development
Director, Research Centre, King Faisal Specialist Hospital
Riyadh, Saudi Arabia

Dr Robert Burton

Professor, School of Public Health and Preventative Medicine
Monash University
Melbourne, Australia

Dr Nausherwan Burki

Professor of Medicine, Division of Pulmonary

Medicine
University of Connecticut Health Center
Farmington, CT United States

Dr Sidnei Epelman

Director, Paediatric Oncology
Santa Marcelina Hospital, Sao Paulo, Brasil

Dr Ian Magrath

President, INCTR, Brussels, Belgium

Dr Donald Maxwell Parkin

Chairman of the Board,

INCTR UK Challenge Fund
Honorary Senior Researcher Fellow
CTSU – University of Oxford, United Kingdom

Dr Martine Raphael

President, AMCC, INCTR's French Branch
Hopital Bicetre
Paris, France

Mr Louis Schoofs

Secretary/Treasurer, INCTR
Former Chief Administrator
Institut Pasteur
Brussels, Belgium

Dr Simon Sutcliffe

President, Two Worlds Cancer Collaboration (INCTR Canada)
President, Canadian Partnership Against Cancer
Vancouver, BC Canada

Ambassador for Science

Dr Harald zur Hausen

Nobel Laureate in Medicine, Deutsches Krebsforschungszentrum, Heidelberg, Germany

Partner institutions in developing countries: Past and present

Africa

- ➔ Obafemi Awolowo University Teaching Hospitals Complex (Ile Ife, Nigeria)
- ➔ University College Hospital, Ibadan (Ibadan, Nigeria)
- ➔ Hôpital Général de Yaoundé (Yaoundé, Cameroon)
- ➔ Kenyatta National Hospital, University of Nairobi (Nairobi, Kenya)
- ➔ Bugando Medical Center (Mwanza, Tanzania)
- ➔ Muhimbili National Hospital (Dar es Salaam, Tanzania)
- ➔ Ocean Road Cancer Institute (Dar es Salaam, Tanzania)
- ➔ Tikur Anbessa Hospital, University of Addis Ababa (Addis Ababa, Ethiopia)
- ➔ St Mary's Hospital Lacor (Lacor, Uganda)
- ➔ Hôpital de Vanga (Vanga, Democratic Republic of Congo)
- ➔ Institut Ophthalmologique Tropical Africain, (Bamako, Mali)
- ➔ National Cancer Institute (Cairo, Egypt)
- ➔ Hôpital du Point G, Université de Bamako (Bamako, Mali)

- ➔ Centre Pasteur du Cameroun (Yaoundé, Cameroon)
- ➔ Université Cheikh Anta Diop (Dakar, Sénégal)
- ➔ CHU Mohammed VI (Marrakesh, Morocco)
- ➔ Clinique Universitaires, Faculté de Médecine de Kinshasa (Kinshasa, Democratic Republic of Congo)
- ➔ Clinique Universitaires, Université de Lubumbashi (Lubumashi, Democratic Republic of Congo)

America

- ➔ Santa Marcelina Hospital (Sao Paulo, Brazil)
- ➔ Instituto Nacional de Pediatría (Mexico City, Mexico)
- ➔ Instituto Nacional de Enfermedades Neoplásicas (Lima, Peru)
- ➔ Universidad Francisco Marroquin (Guatemala City, Guatemala)
- ➔ El Instituto Oncologico Del Oriente Boliviano (Santa Cruz, Bolivia)

Asia

- ➔ Ankara University (Ankara, Turkey)
- ➔ Hacettepe University (Ankara, Turkey)

- ➔ Dokuz Eylül University (Izmir, Turkey)
- ➔ King Hussein Cancer Center (Amman, Jordan)
- ➔ King Faisal Specialist Hospital (Riyadh, Saudi Arabia)
- ➔ Children Cancer Institute, Ziauddin Medical University (Karachi, Pakistan)
- ➔ Jinnah Hospital Lahore – Allama Iqbal Medical College (Lahore, Pakistan)
- ➔ Shaukat Khanum Memorial Cancer Hospital and Research Centre (Lahore, Pakistan)
- ➔ All India Institute of Medical Sciences (New Delhi, India)
- ➔ Cancer Institute (WIA) (Chennai, India)
- ➔ Jaslok Hospital and Research Centre (Mumbai, India)
- ➔ MNJ Institute of Oncology (Hyderabad, India)
- ➔ Tata Memorial Centre (Mumbai, India)
- ➔ Nepal Institute of Health Sciences (Kathmandu, Nepal)
- ➔ B P Koirala Memorial Cancer Hospital (Bharatpur, Chitwan, Nepal)
- ➔ Bhaktapur Cancer Care

- Hospital (Bhaktapur, Nepal)
- ➔ Hospice Nepal (Kathmandu, Nepal)
- ➔ Kanti Children's Hospital (Kathmandu, Nepal)
- ➔ Shechan Hospice (Kathmandu, Nepal)
- ➔ Scheer Memorial Hospital (Banepa, Nepal)
- ➔ Patan Hospital (Kathmandu, Nepal)
- ➔ Philippine Children's Medical Center (Quezon City, Philippines)
- ➔ Shanghai Children's Hospital (Shanghai, China)
- ➔ Sarawak General Hospital and Sarawak Hospice Society (Kuching, Sarawak, Malaysia)

Latin America

- ➔ Santa Marcelina Hospital (Sao Paulo, Brazil)
- ➔ Instituto Nacional de Pediatría (Mexico City, Mexico)
- ➔ Instituto Nacional de Enfermedades Neoplásicas (Lima, Peru)
- ➔ Universidad Francisco Marroquin (Guatemala City, Guatemala)
- ➔ El Instituto Oncologico Del Oriente Boliviano (Santa Cruz, Bolivia)

Partners: Past and present

ORGANIZATIONS

World Health Organization (NGO in Official Relations)
 International Agency for Research on Cancer
 International Atomic Energy Agency/PACT
 Union for International Cancer Control
 European School of Oncology
 European Society of Medical Oncology

NGOs

American Cancer Society
 The Australian Cervical Cancer Foundation
 Augusta Victoria Hospital
 Breast Global Health Initiative
 Doris Duke Charitable Foundation
 Global Giving
 Hospice Africa France
 ICEDOC
 Jiv Daya Foundation
 Open Society Institute
 The Aslan Project
 TUCCA

PHARMACEUTICAL COMPANIES AND THEIR FOUNDATIONS

CIPLA Foundation
 Eli Lilly
 Glaxo Smith Kline
 Novartis Brasil
 Roche
 Sanofi-aventis – Fondation sanofi-espoir

ACADEMIC INSTITUTIONS

Georgetown University, Washington, DC USA
 Hopital Bicetre, Paris, France
 Imperial College, Hammersmith Hospital, London, UK
 Institut Curie, Paris, France
 King's College Health Partners, London, UK
 Nainamo Hospice, British Columbia, Canada
 National Cancer Institute of Brazil, Rio de Janeiro, Brazil
 National Cancer Institute of France, Paris, France
 University of Basel, Switzerland
 University of Ghent, Belgium
 University of Lund, Sweden
 University of Siena, Italy

GOVERNMENTS

Government of Australia, Australian Embassy, Nepal
 Government of Brazil
 Government of Ethiopia
 Government of Mali
 Government of Nigeria
 Government of Sénégal
 Government of Tanzania
 Government of Uzbekistan

COMMERCIAL COMPANIES

AGFA-Gaeverts
 ESMO
 Global Health Dynamics

www.cancercontrol.info