Working with National TB Programs Across Two Continents: 
*Opportunities and Challenges*

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**Consultation Meeting to Strengthen Engagement of Civil Society Organizations in the TB Area of Work of the WHO**

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NGOs (or CSOs) who are working at the grassroots level and confronting the human suffering due to TB are often the first to be aware of unmet needs, literal vacuums and obstacles to TB care in contexts that are both specific to particular countries and that also transcend borders.

NGOs are in a unique position to develop novel solutions that establish proof-of-principle for national programs and for international transfer and are a natural partner for WHO in its advisory role for MOHs and in its strategic planning roles for dealing with the TB crisis.
Delivery and Discovery: Cambodian Health Committee

Delivery of community based care to treat TB and HIV/AIDS since 1994

Operational models to treat TB and AIDS that can be used globally

Hypothesis driven research to:
• understand the molecular basis of the natural history of disease;
• to maximize use of drugs we have in hand

Advocacy for the right for all people to have access to treatment for TB and AIDS
The beginnings of CHC: active war zone of the 1980’s Thai-Cambodian border

Site 2 Refugee Camp, 1989
American Refugee Committee (ARC) Hospital
The arguments voiced against TB treatment in 1981:

The camp population was unstable in an active war zone, people had open access to come and go to Cambodia (although fenced by barbed wire and Thai military from going into Thailand)

• 6 months of therapy required for cure, how could refugees in this situation do it?
• The Cambodian medical staff poorly trained and motivated
• Surely, such a program would only create a disastrous situation of poor compliance and increased drug resistance of the TB

But, up to 50% of TB patients without medicine die of a curable disease
Features of the ARC Program: Pioneering TB treatment in a war zone

Separate and accessible clinic with bilingual supervisor pioneering Daily Observed Therapy (DOT) treatment protocol for 6 months beginning in 1981

- **No cost to refugees**
- **Provision of food rations**
- **Education about the disease**
- **Signed treatment contract**
- **Identification of a patient supporter who commits to help the patient achieve cure**
- **Vitamin protocol for learning and showing how to take drugs**
- **Training health workers--Sok Thim trained and took over as TB coordinator in 1988**
A Stunning success: the first demonstration of treating refugees in a war zone for TB
Results of the first 58 patients published in 1984

Steven H. Miles and Robert B. Maat
Am Rev. Respir Dis 1984; 130: 827-830

58 patients for 6 months
only 15 of 10,209 patient days missed

eventually by the end of the border camps in 1993 over 10,000 patients were cured.

Red Hill Evacuation site, Thai-Cambodian border 1983
In 1994, the Cambodian Health Committee (CHC) developed a novel community-based approach to TB and later to AIDS treatment.

- Svay Rieng Province is one of the poorest of Cambodia’s 10 provinces (aver. yearly income for family of 9 approx $220) and
- In 1994, the highest prevalence of TB (700/100,000)
Ruomduol Hospital, Svay Rieng, Cambodia, 1995
CHC PHILOSOPHY:
Everyone wants to be well and their family to be well and given Access to medicines and the proper support can complete a long and difficult therapy towards that goal.
CHC Approach beginning in 1994

• Working within NTP guidelines: forced hospitalization at the time for intensive phase (until 1997)

• Pretreatment patient education

• Identification of a patient supporter

• The signing of a TB treatment contract by patient, patient supporter and health worker

• Provision of Food (throughout treatment); pioneered with WFP, then nationwide

• Linkage of a microfinance project including village banks and village health agents-1995-2002

• Working closely with the NTP to provide training and sustainability: now methodology part of NTP program

• Home DOT in areas of Svay Rieng-beginning in 1999

• Integration of TB and AIDS services

• Community DOTS piloted to 1 million people in 2006-2007 in Svay Rieng and Kompot Provinces: cure rate 95% and new case detection ~75%; now being scaled up countrywide
Almost impossible for most patients to access the health centers on a daily basis due to poor roads and poverty
TB Home and Community DOTS: leveraging the social collateral--the family and community--delivering care at home by CHC/NTP team 5 days/week and by patient supporters on the weekends
Delivery and  Discovery and Filling the Gaps
Cambodian Health Committee TB and AIDS Programs

CHC Rural TB:  June 1994-March 2010
Svay Rieng, Kampot, Kandal Provinces:
~25,000 Cured
Scale-up Community DOT approach to entire country of 15 million

CHC Rural AIDS: July 2004-March 2010
Svay Rieng and Kampot Provinces
>4000 in follow-up

MDR Universal Access in Cambodia

CHC Urban Centers of Excellence: for TB and AIDS in Phnom Penh
Pulmonary Ward rehabilitation of KFSH (largest public hospital in Cambodia (900 HIV+ adults on ARV follow up)

Rural and Urban Children’s Program for TB and AIDS:
• Maddox Chivan Children’s Center
• KFSH Pediatric Ward and new outpatient clinic (381 HIV+ children)
• Svay Rieng: pediatric HIV cohort: 125; Prevalence of TB in 1000 rural children study

Ongoing Research to impact delivery of care with evidence based research
CAMELIA
Diagnosis of TB in children in rural Cambodia
17 yo CSW advanced AIDS and PTB,
Khmer Soviet Friendship Hospital (KSFH) Pulmonary Ward, Phnom Penh 2001

Largest public hospital in Cambodia

No ART available
Cambodia: First HIV-1+ 1991; First AIDS case 1993

Photo: James Nachtwey, Phnom Penh 2003
The First 36 found in TB HOME Care project on Home ARV for 5 months then followed in new rural clinic (4 year follow up):

3 dead
No detectable viral load in 33 survivors

80% CD4<50 at initiation

Patient #2 (of first 36)
Jan 2004: CD4 12
March 2008: CD4 153

Svay Rieng, March 2008

CHC begins HIV care in rural Cambodia
TB and AIDS: Linking Implementation and Basic Discovery to Fill the Gap of Care delivery and Knowledge

CIPRA-NIH
Comprehensive International Program for Research on AIDS
Building a TB and AIDS clinical and research network in Cambodia: upon the CHC grassroots clinical care and research program

CAMELIA
CAMbodian Early versus Late Introduction of Antiretrovirals (in TB patients with AIDS and CD4 <200)
Starting ARVs at 2 weeks or 2 months after starting TB therapy

CHC/ANRS/NIH
5 clinical sites in Svay Rieng and Kampot provinces, Phnom Penh and Siem Riep: goal of recruiting 660 patients in 2006

First US (NIH)-French (ANRS) Trial in a resource-poor country
Cambodian Health Committee/HMS/Institut Pasteur
ANRS 1295/12160 - CIPRA KH001/10425 study
CAMELIA: Cambodian Early vs Late Introduction of ART

Strategy:

ANRS 1295/12160 - CIPRA KH001/10425 study
CAMELIA: **Cambodian Early vs Late Introduction of ART**

**Significant Reduction of Mortality in the Early Arm**


ANRS 1295/12160 - CIPRA KH001/10425 study

Presented at IAS July 2010
NUMEROUS SIDE BENEFITS of the SCIENCE AND THE CAMELIA/CIPRA:

Infrastructure and capacity vastly improved

Creating centers of excellence for TB & HIV care and research
The 1st CAMELIA MDR patient shown a year into her therapy in July 2008: 35 yo with MDR then on treatment and 6 yo daughter on ART

Other Collateral Benefits
Access to MDR Rx and access to care

Since we were going to perform DST on all 660 CAMELIA patients, we expected to find ~30 MDR & thus made the first application to the WHO Green Light Committee (GLC) on behalf of from Cambodia

Photo: Svay Rieng Province 2008
20% of Cambodian MDR-TB patients initiated therapy as outpatients with Patient Supporters in CHC-NTP Partnership

Extensive Outpatient Monitoring System Established

Svay Rieng, Cambodia 2008
Delivery and Discovery and Filling the Gaps
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CAMELIA
Diagnosis of TB in children in rural Cambodia
TB in Ethiopia

- Ranks #7 among the 22 highest TB-burdened countries.
- Ranks #15 among the 27 highest MDR-TB-burdened countries
MDR TB in Ethiopia in 2008

Population ~80 million

129,000 new TB cases/year
(1.6% MDR & ~12% MDR in retreatment cases)
~6,000 new MDR cases/year

221 MDR cases documented by DST as of 8/08 in Addis Ababa area; FIND assistance to establish lab capacity

Green Light Committee (GLC) application initiated 2007 and submitted June 2008

GLC approval for 45 patients was in process in Sept 2008, with anticipated start date of October 2008

Cambodian Health Committee team visit to St Peter’s Hospital, Addis Ababa August 2008 to assist initiation of Ethiopian MDR program
South-South Partnership: Didactic Training in Addis (Oct 2008), And then Ethiopian MDR Team Trains in Cambodia

Battambang, Cambodia, December 2008
Limitations Faced in Ethiopia in Feb 2009:

- No second line TB drugs
- Isolation beds not available
- Human resource limitations
- 2nd line pharmacy not in place
- Only partial lab testing available
- Outpatient system not established

Cambodian/Global Health Committee (GHC) procured drugs (Lilly and Chao Center donations) and using models established in Cambodia, the Ethiopian MOH/GHC MDR team initiated MDR care at St. Peter’s Hospital in Feb. 2009
**Ethiopia MDR-TB Timeline June 2007 – October 2010**

- **6/2007** Green Light Committee (GLC) application process started
- **6/2008** GLC application submitted
- **8/2008** GLC application approved for cohort of 45—planned program start date Oct. 2008
- **9/2008** CHC/GHC provides drugs for the first patient
- **10/2008** First GHC MDR training of doctors, nurses and health workers in Addis Ababa
- **12/2008** CHC training of Ethiopian MDR team in Cambodia
- **2/2009** First cohort of Ethiopian MDR patients started on GHC drugs at St. Peter’s Hospital
  - First cohort of 8 patients start therapy with GHC and Lilly drugs in GHC/FMOH program
- **6/2009** Second cohort of 13 GHC patients started
- **8/2009** Third cohort of 16 GHC patients started
- **9/2009** GLC drugs arrive in Ethiopia
- **10/2009** Fourth cohort of 14 patients started
- **12/2009** Fifth cohort of 30 patients started
- **1/2010** Sixth cohort admitted (13 patients)
- **3/2010** Seventh and Eight cohorts admitted (44 patients, including 5 outpatient starts)
- **5/2010** Ninth cohort admitted (12 patients)
- **7/2010** Program initiation in northern Ethiopia, Gondar (3 patients)
- **9/2010** Currently 127 patients on therapy; 8 deaths; 100% adherence
Status of GHC/Ethiopian MOH MDR-TB Program as of September 2010

• To date 127 initiated on therapy
  - 74 with medication provided by the Global Health Committee (GHC)
  - 45 with medications provided by the Green Light Committee (GLC)
  - All inpatients and outpatients supported by GHC technical and financial support
  - 25% co-infected with HIV-1
  - Mean # of prior treatments: 3

• **93 patients are currently on outpatient follow-up at home** (community based therapy) using patient supporters, social and nutritional support based on Cambodian ‘CHC’ model

• **0 defaulters**

• 8 patients have died on therapy

• All eligible back-log patients who could be found were started on therapy

• expansion out of Addis to Gondar begun: nursing and medical staff trained at St. Peter’s
The First Cohort: the first 8
February 2009

Addis Ababa, February 2009

Back-log patients and MDR suspects among retreatment cases in homeless shelter

19 yo with severe malnutrition, HIV negative and 3 prior failed treatments (Cat I and Cat II x 2), admitted with pulmonary and disseminated TB.
The First Cohort: June 2009

7/8 achieved bacteriologic conversion; 1 death. All currently managed as outpatients and on 18th month of Rx.
Ethiopia MDR Time Line

Of the historic **221 DST-confirmed MDRTB backlog patients** in Addis Ababa awaiting 2nd line therapy in August 2008:

**20%** of list confirmed **dead** while awaiting therapy

**50%** of list were unable to be located with the contact info in hand despite door to door search by GHC staff, many presumed dead

All coughing and smear +

MDR-TB Home Visit, Addis Ababa 2010
Advanced, chronic patients with extensive bilateral disease: 
* CXR examples of randomly selected patients upon entry
Overall problem:
MDR-TB diagnostic and treatment levels far too low

511,000 estimated cases

No diagnosis and treatment reported. Some treatment probably obtained, quality unknown

Countries report diagnosis and treatment, standard unknown

Diagnosed and treated in Green Light Committee programmes
South-to-South transfer of an integrated approach of hospitalized based and community based treatment, which has proved highly successful in treating MDR in Cambodia has filled the gap in Ethiopia and provided access to MDR care and provides a model for expansion.

Rapid Scale-up is Possible

Ethiopian MDR team training in Cambodia Dec. 2008
CHC/GHC Grassroots Knowledge and Solutions: Filling the Gaps

Examples:

**TB care in a war zone:**
- Initiating DOTS in a refugee camp in the active war zone of the Thai-Cambodian border for Cambodians who had no access to TB care at all

**Community Based TB care in Cambodia beginning in 1994**
- Leveraging family and neighbors to be patient supporters and initiating Food distribution with outpatient distribution of TB meds with WFP in 1994 to aid in adherence
- Integrating microfinance with TB care in rural Svay Rieng and Kompot Provinces to combat poverty, aid in adherence and help with new case finding
- Initiating home DOT for rural Cambodians too far from regional hospitals to access care and to reach more people with active case finding
- Initiating community DOT and piloting it in 2 provinces, now in national scale-up -

**Access to HIV care**
- Initiating TB/HIV integration at provincial and rural level and creation of centers of excellence for TB/HIV care for adults and children through delivery and discovery

**Access to MDR care**
- Community and hospital based approach in Cambodia and transfer to Ethiopia
NGOs are in a unique position to develop novel solutions that establish proof-of-principle for national programs and for international transfer

Other CHC/GHC Examples:
• SYNERGY OF DELIVERY AND DISCOVERY:
  Using Research and Clinical Trials to enhance care:
    The CAMELIA trial to determine optimal timing of ART in TB/HIV co-infection and to integrate rural and urban TB/HIV care
    Optimal approach to diagnosing TB in Children

• Multidisciplinary and Integrated Medical/Social/Educational Approach for children with TB and HIV

• South-to-South Transfer from Cambodia to Ethiopia
Sustainability and Scale up:  
the CHC/GHC Experience

Critical to work in partnership with national programs and national structures and to integrate and train NTP staff in all initiatives from the outset in order to ensure that programs are not ‘boutique’ solutions. This often leads to finding a ‘middle way’, but such a way is sustainable

Examples:
Community based TB care in Cambodia: revolutionary in 1994, now nationwide

Provincial AIDS care in Cambodia: HOME DOT to hospital based access to meds

AIDS care for children in Cambodia
Advocacy in Real Time

NGOs are in the position to be visionary about issues as they develop in real time and to motivate the humanitarian agenda around specific TB issues from their grassroots experience.

CHC/GHC Examples:

- Highlighting the TB/HIV catastrophe and lack of access for care in SE Asia through photography in collaboration with James Nachtwey beginning in 2003 and in writing in mass media and through highlighting HIV/TB through scientific symposia, ie IAS 2005 & Gates/Keystone Tanzania 2009

- Highlighting and assisting treatment of TB in disenfranchised populations in war zones & refugee populations on Thai-Cambodian border (1980s), assisting on Thai-Burma border and in Pakistan and Afghanistan

- Focus international scientific agendas on TB/HIV through operational, clinical trials and basic research and national funding agencies and collaborations, ie NIH and ANRS in Camelia Trial

- Focus on children with TB: diagnostics and care: current diagnostics study in Svay Rieng

- Provision of drugs for XDR TB in Vietnam

- Highlighting the inadequate response to MDR/XDR TB through initiation of MDR Programs in Cambodia and Ethiopia with respective MOHs
WHO’S UNIQUE POSITION AS ADVISOR: OPPORTUNITIES AND RESPONSIBILITIES

Open WHO mindset is key:
When MOH/NTP is unable to deliver a critical program, NGO-led initiatives should be supported

Examples:
- **MDR TB programs of Cambodia and Ethiopia**
- Using research like from the CAMELIA to change guidelines
- Community based TB care
- TB care access for refugees

When initiatives are not working, urgent action and evaluation needed

Example:
**GLC and MDR drug access and procurement**
NGO’s and CSO’s can fill gaps and provide critical technical and ground level experience to national programs and WHO through:

- identification of problems in delivering TB care and developing grassroots solutions
- raising awareness around issues as they appear in real time and sharing ground level solutions that work

WHO support of effective NGO-initiated approaches or new initiative to fill gaps

**Funding Access Key:** Direct access to funds from GF

- One potential solution: *independent* coalition of NGOs/CSOs to be a third formal partner in problem solving and advocacy related to TB along with MOHs and WHO would be a potential model, eg the successful model of the International Campaign to Ban Landmines
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NIH • ANRS • Eli Lilly MDR Partnership
Everyone has the right to life, liberty, and security of person

*Article 3, Universal Declaration of Human Rights*
FAILURE IS NOT AN OPTION